PROCEEDINGS

Fifth Annual Conference
of the
Model Reporting Area
for
Blindness Statistics
1966

U.S. DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
Public Health Service

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PROCEEDINGS

Fifth Annual Conference of the Model Reporting Area for Blindness Statistics 1966

Boston, Massachusetts
May 19–20, 1966

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U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
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PROCEEDINGS OF THE FIFTH ANNUAL CONFERENCE OF THE MODEL REPORTING AREA FOR BLINDNESS STATISTICS BOSTON, MASSACHUSETTS MAY 19–20, 1966

I. INTRODUCTION

The Fifth Annual Conference of the Model Reporting Area for Blindness Statistics (MRA), sponsored by the National Institute of Neurological Diseases and Blindness (NINDB),[1] in cooperation with the Division of the Blind, Massachusetts Department of Education, was held on May 19–20, 1966, in Boston, Mass. The agenda of the Fifth Annual Conference was concerned with the progress and development of the MRA, blindness statistics produced from the MRA program, status report on the Index and Standard Classification of Causes of Severe Vision Impairment and Blindness, exploration of the use of blindness registers for screening of persons with homocystinuria, proposal for a continuing analysis of MRA register experience, and selected current activities and research in blindness and severe vision impairment which related either directly or indirectly to the Model Reporting Area.

In attendance at the Fifth Annual Conference were the administrators and/or registrars or their representatives from all 14 member States, including the States of South Dakota and Utah which were formally admitted to the MRA at the Conference; representatives from 6 nonmember States, and representatives from various Federal agencies, national and State voluntary and private agencies, and other institutions concerned with the problem of vision impairment. The MRA States represented were Connecticut, Kansas, Louisiana, Massachusetts, New Hampshire, New Jersey, New Mexico, North Carolina, Oregon, Rhode Island, South Dakota, Utah, Vermont, and Virginia. Nonmember States represented were the District of Columbia, Georgia, Maryland, Michigan, New York, and Texas. Attending from voluntary agencies were representatives of the American Foundation for the Blind, the National Society for the Prevention of Blindness, and the Canadian National Institute for the Blind. The following national private agencies were represented: Catholic Guild for All the Blind including the American Center for Research in Blindness and Rehabilitation, Rehabilitation Codes, and Research To Prevent Blindness. Federal agencies with blindness programs which were represented at the Conference included the Library of Congress, the Bureau of State Services, the National Center for Health Statistics, and the National Institute of Neurological Diseases and Blindness of the Public Health Service. Other agencies and institutions represented were Morgan Memorial, Russell Sage Foundation, Brandeis University, Johns Hopkins University, Massachusetts Insitute of Technology, Perkins School for the Blind, and University of Alexandria, Alexandria, Egypt.

Dr. Hyman Goldstein, Chief of the Biometrics Branch, NINDB, presided at the 2-day Conference. Dr. Goldstein, speaking for the NINDB and the Model Reporting Area, commended with gratitude the efforts of the Division of the Blind, Massachusetts Department of Education, in its role as host to the Fifth Annual Model Reporting Area Conference.

Mr. John F. Mungovan, director, Massachusetts Division of the Blind, in welcoming

[1] National Institutes of Health, Public Health Service, U.S. Department of Health, Education, and Welfare.

the conferees, expressed the pleasure of his division in hosting the Conference and his hope for a very productive, interesting, and pleasurable meeting.

II. SPECIAL PRESENTATIONS

a. Dr. Victor A. McKusick, Professor of Medicine, The Johns Hopkins Hospital, Baltimore, Md., presented a paper on "Homocystinuria Screening Project." (See app. A for this paper and discussion which followed.) A summary of the paper appears below.

SUMMARY

Dr. McKusick stressed that blindness registers could be very valuable sources of material for the investigation of specific entities which require access to specific patient groups. This point is of particular importance when such entities involve hereditary factors. With reduction in this country in blinding disorders based on infectious and nutritional etiologies, those that are genetically determined, in whole or in part, are assuming greater importance.

Dr. McKusick stated that homocystinuria is a genetic defect in metabolism in which progressive myopia and dislocation of the lenses occur in the first decade of life. It appears that proper dietary treatment initiated early can arrest the progression of the disease and perhaps cause some restitution toward normal. Consequently, for practical as well as scientific reasons it is worthwhile to try to identify all cases. This can be done by the cyanide-nitroprusside test applied to urine from patients with dislocated lenses or suspected Marfan's syndrome which is somewhat similar to homocystinuria.

He asked the MRA States for their assistance in securing the cooperation of those on the blindness register who have dislocated lenses or suspected Marfan's syndrome to furnish a urine sample. He stressed that the confidentiality of the register would be preserved, the privacy of the patient maintained, and the cooperation of the reporting physician sought.

b. Dr. Hyman Goldstein, Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness, presented a paper on "Review of Development of the Model Reporting Area for Blindness Statistics." (See app. B for this paper.) A summary of the paper appears below.

SUMMARY

Dr. Goldstein reviewed the growth of the Model Reporting Area for Blindness Statistics (MRA) from its inception in 1962. In this process, certain deficiencies in geographic coverage of the MRA have become apparent. In view of the fact that geographic coverage and ethnic group coverage are related, expansion of the MRA to include certain key States is vital if urgently needed national estimates of the prevalence and incidence of blindness by age, sex, race, cause of blindness, etc., are to become available. Another problem stressed by a panel that reviewed the activities of the MRA, is concerned with the need for studies of completeness of reporting of blindness in the various MRA States and in States to be admitted to MRA in the future. Also needed are studies of the reliability and validity of the data submitted by reporting sources to MRA registers. Such studies would be undertaken as soon as possible and as funds and personnel permitted.

c. Dr. Ralph G. Hurlin, chairman, Subcommittee on Classification, Committee in Operational Research, National Society for the Prevention of Blindness, presented a paper on "The Standard Classification of Causes of Severe Vision Impairment and Blindness." (See app. C for this paper and discussion which followed.) A summary of the paper appears below.

SUMMARY

Dr. Hurlin first spoke briefly concerning the present status of the National Society for the Prevention of Blindness (NSPB) standard classification plan, which has been used by the MRA States since 1963, but his main emphasis concerned the need for supplementing the standard classification by procedures standardized in other important aspects, if valid statistics are to be obtained. He expressed belief that the NSPB classification had been

greatly improved as a result of its adoption and use by MRA, partly through the "not drastic" changes which had been made in its categories, but chiefly due to the development, jointly by the NSPB committee and the MRA staff, of the extensive, coded Index of Diagnostic Terms that now provides definition of the previously indefinite categories. He indicated that need would be found for more changes in the categories, and hoped that they would be made as need for them is seen. He stressed the importance of the detailed statistics that are obtained by cross-classification of type of affection by etiology, and the desirability of publishing the detailed statistics, holding that separate statistics for the two parts of the classification were not of great value.

Referring to the acceptance of the principle of the NSPB classification in other countries, Dr. Hurlin said that while much is to be gained from the use of essentially comparable classification plans, standardization of classification is not enough to insure comparability and soundness of cause statistics. He then proposed and discussed briefly the following six requirements as necessary parts of a satisfactory total standard procedure for the production of cause-of-blindness statistics, commenting concerning each on the present MRA procedure:

1. Use of a standard definition of the indefinite term "blindness." MRA provides such a definition.
2. Collection of diagnostic data only from physicians who are specialists in ophthalmology. MRA makes this requirement.
3. Collection of diagnostic data through, and acceptance of such data from, only mature registers of blind persons. In a mature register, the proposed additions and removals will be in approximate balance. MRA does not make this requirement.
4. Use of a standard twofold plan of classification. Such a classification, developed by NSPB, is used by MRA.
5. Use of standard coding procedures. MRA makes this requirement.
6. Use of a standard report form in the collection of diagnostic data from physicians. MRA does not make this requirement. Dr. Hurlin expressed hope that, with respect to the proposed requirements 3 and 6, MRA's procedure could be modified for the coming year.

d. Mr. Irving D. Goldberg, Assistant Chief, Biometrics Branch, NINDB, presented a paper on "Proposal for a Continuing Analysis of Model Reporting Area Register Experience." (See app. D for this paper.) A summary of the paper appears below.

SUMMARY

Mr. Goldberg referred to the recently completed and published study on the survivorship and causes of death among the blind, conducted by the Biometrics Branch, NINDB, with the cooperation of the Massachusetts Division of the Blind. The success of that study led the Biometrics Branch to the consideration of a longitudinal study of the subsequent status and survivorship patterns of persons registered as blind with the Model Reporting Area (MRA) States. The way the registers are being maintained in the MRA States makes it feasible to conduct such a study on a continuing basis in a prospective manner, without any material burden to the States themselves. The key to the proposal is the prospective nature of the study by which persons would be followed from the time of registration until they die or are otherwise removed from the register, or until a fixed number of years has passed.

Mr. Goldberg discussed the various objectives of the study as they related to survivorship rates, causes of death, sight recovery rates, readmissions to the register, migration patterns, and effects of various services on survivorship.

Sources of information for the study would include the records of the blindness agencies in the Model Reporting Area States, the death certificates from the vital statistics officers of the MRA States, and certain published data from the National Vital Statistics Division.

Mr. Goldberg suggested that it may be desirable to initiate the proposal on a pilot basis, by confining the activity to one State for perhaps 1 year, so as to determine what some of the problems might be and to provide a means for streamlining the methodology for application to other MRA States.

With regard to the starting point for the study, Mr. Goldberg offered various alternatives, but he suggested that it probably would be most desirable to start with current additions to the register in the year in which the study is initiated and also to include in the continuing followup all subsequent additions through the life of the study.

A life-table type of analysis by sex, race, and cause of blindness, similar to that used in the Massachusetts survivorship study, would be employed. The analyses will be conducted both on an individual State basis as well as for the MRA as a whole. Mr. Goldberg stated that various details as to specific types of analyses and specific procedures would have to be worked out.

e. Dr. M. E. Said, professor of ophthalmology, Faculty of Medicine, University of Alexandria, Alexandria, Egypt, presented a paper on "The Blindness Register Survey in Egypt." This paper was prepared by Dr. Said, Dr. A. Korra, project control officer, and Dr. K. El-Kashlan, chief statistician, the Blindness Register Survey in Egypt. (See app. E for this paper.) A summary of the paper appears below.

SUMMARY

Dr. Said gave a preliminary report on a survey of visual acuity with best correction and field of vision of the population in two urban areas in Alexandria, Egypt, and in 23 villages outside that city. The project, started in March 1965 and to run for 3 years, is a cooperative one between the University of Alexandria and the National Institutes of Health and is financed by Public Law 480 funds.

The objectives of the project are: (1) To determine what, if any, modifications may be made in Model Reporting Area procedures to get comparable blindness statistics in a less developed country; (2) to determine the prevalence, incidence, and causes of blindness in Egypt in specified urban and rural areas.

There are three phases to the study: (1) Phase I, designed to secure data on the prevalence of blindness by age, cause, sex, etc., involved the visual screening of a random sample of approximately 4 percent of the households in the urban and rural areas; (2) Phase II was designed to build up a blindness register by visually screening as many persons as possible of the approximately 125,000 urban persons and 125,000 rural persons in the areas under study on the basis of a voluntary visual screening examination; and (3) Phase III was designed to secure data on incidence of blindness by age, sex, cause, etc., in a random sample of approximately 4 percent of the households in the urban and rural areas under study in Phase I by reexamining approximately 18 months later those of the individuals examined in Phase I who were still living. By comparing the data of Phases I and III, the incidence may be ascertained.

Findings of Phase I were as follows:

1. Approximately 40 percent of those examined in urban areas were male and about 60 percent, female. In the rural areas the percents were 49 and 51 respectively.
2. In the urban area, about 55 percent of the examinees were under 25 years and 3 percent were 65 years and over. Corresponding percentages in the rural areas were 48 and 2. No significant differences were evident between the age distributions of males and females.
3. The urban blindness prevalence rate was 1,437 per 100,000 for both sexes, with rates of 1,198 for males and 1,600 for females. In the rural areas the blindness prevalence rate for both sexes was 4,679 per 100,000 with rates of 3,360 and 5,962, respectively, for males and females. The rates for females were consistently higher than male rates, irrespective of size of village. The difference between urban male and female rates was not statistically significant. However, that between rural male and female rates was significant at the 5-percent level. Similarly, the difference between urban male and rural male rates was significant as was that between urban female and rural female rates.
4. Although those under 25 years in the urban areas accounted for 55 percent of

those examined, the blind under 25 years represented about 7 percent; those 65 years and over represented about 3 percent of those examined and 29 percent of the blind. In the rural areas, those under 25 years composed 48 percent of the population examined but only 8 percent of the blind; those 65 years and over comprised only 2 percent of those examined and 25 percent of those found to be blind.

5. The urban age-specific prevalence rate rose from the youngest age group to the oldest, with marked increases noted in the groups above age 45. However, the female rate reached its peak in the age group 65–74 years and then decreased somewhat. The rural age-specific prevalence rate also rose reaching its peak at age 75 years and over in which age group two of every three members were found to be blind. The female rates were higher than male in each age group and their increases with age more marked. Such increases in rate with age were generally found irrespective of size of village.
6. The prevalence rates for all affections combined as well as those for cataract, purulent ophthalmia, corneal ulcer due to bacterial infection, and glaucoma were considerably greater in the rural areas than in the urban ones. Only myopia failed to show this picture. Cataract had the highest prevalence rates for males and females in the urban areas with purulent ophthalmia rates following in magnitude. This picture was reversed in the rural areas with purulent ophthalmia leading the list of affections, followed by cataract. Since the etiology of purulent ophthalmia is an infectious disease, it would seem that the problem of infection, as it concerns the etiology of blindness, is more acute in the rural areas than in the urban ones. In both urban and rural areas the prevalence rates rose with age. However, in some affections there was a leveling off at age 65–74 years. Female rates exceeded those for males in the urban areas for all affections combined and for all specified affections except corneal ulcer due to bacterial infection, and myopia. In the rural areas female rates were greater than male ones for all affections combined and for every specified affection tabulated.

III. PROGRESS IN MODEL REPORTING AREA STATES DURING 1965

CONNECTICUT: Mr. McCollam indicated that in his opinion Connecticut definitely has made good progress in the past year. A thorough "housecleaning" of the register has been accomplished to the point where all the figures deriving from the register are considered to be solid. All persons on the register are followed up at least annually. A check in 1965 of the total register of some 3,200 names revealed that only 166 persons had not received some individual service from the agency during the year. Only 2 persons of the 166 could not be located through letter, phone, or personal contact. Mr. McCollam felt that the intensity with which his agency has worked on updating the register has paid off with a really accurate count. He touched on a number of problems facing his agency. Among these was the change in coding rules that had been instituted during the past year. He wondered whether there was need for such "ultra refinement" of the coding. The coders can only work with what is on the eye report form. Another problem had to do with the difficulty of coding certain multiple causes. He looked forward to publication of the manual of coding instructions by the National Society for the Prevention of Blindness as a means of helping the coders in this general area. He thought that the mid-February deadline for submission of punchcard decks to NINDB did not allow sufficient time for the necessary data processing and wondered whether other States had the same problem. Mr. McCollam concluded by stating that his program is going very well and that the agency was very well satisfied with the results obtained and with the cooperation it has had from the Biometrics Branch, NINDB.

KANSAS: Miss Blase reported progress in securing more complete data for registration, particularly in getting more ophthalmological reports, i.e., about 95–98 percent of all medical

reports are from ophthalmologists. Progress also was made in updating the register by working jointly with the Department of Social Welfare's accounting staff. All medical data are being reviewed for accuracy prior to recording. Miss Blase indicated that more use is being made of the register. The Kansas State Board of Health has used it to develop its safety program. It has been used to develop a register of employed blind by the vocational rehabilitation program, as well as to identify service needs. The State Motor Vehicle Department uses it in connection with drivers' licenses. Miss Blase was of the opinion that there was a problem of underreporting blind persons to the register because some physicians do not report a case unless the person is requesting a specific service from the Division of Services for the Blind. With the advent of medicare and the broadening of public assistance medical care programs, it is probable that the division will be getting even less reports on the blind from physicians. Although at the present time there is a statewide medical program to provide eye treatment to people needing it to restore vision and to prevent blindness, payment for most of these services has been taken over by the State public assistance program which has accounted for the division receiving about 50 percent of its reports on blindness. However, because the welfare program does not require reports, it would appear that fewer reports will be forthcoming. The division's advisory committee has requested that such reports continue to be sent to the division even though the bill for services is being paid by the Department of Social Welfare. Mr. Hayes underscored the concern of the division in continuing to receive medical reports under its eye-treatment program which, since its origin in 1937, has been productive of a large percent of the eye information received. At the time it was established the program provided for eyes a quality of medical service that was unknown for other disabilities. Happily this has resulted in other medical care quality rising to the level it set. Furthermore, the scope has broadened to the point where the eye-care program is being taken over. Although this is a good thing basically, the danger lies in not being able to get eye information from a large part of the population that will be securing public medical care for this type of disability. Both Miss Blase and Mr. Hayes thought that blindness programs in other States would be facing this problem and invited discussion. The new codes, to date, have not created too many problems in Kansas. The State supervising ophthalmologist does most of the coding. For the most part, any questions and any different points of view regarding the coding have been resolved. In closing, Mr. Hayes indicated his interest in determining to what degree his register is underreported. In his opinion the Hurlin estimate of 4,100 legally blind for Kansas was too high. However, in his opinion his register total of 3,200 represents some underreporting but probably is closer to the actual number of blind in the State. He was interested in learning of techniques or methods by which to evaluate the completeness of his register.

LOUISIANA: Mr. Bridges stated that his greatest problem was concerned with updating the register. In 1965 it was found that almost 4,000 of the 6,217 on the register at the beginning of the year were receiving some type of service. The records of the approximately 2,000 persons not getting services were reviewed by the staff. Of these about 800 were identified as still living and blind. A double postcard self-addressed for return by the respondent was sent to the remaining 1,200 registrants. The recipient was asked a few questions about change of address, whether his vision had changed, and whether he was interested in receiving services from the Division for the Blind. Many replies were received. All of the approximately 1,200 recipients were located with the exception of 3. In February 1966 a newsletter was sent to all registrants in order to see whether those persons who were not receiving services might be interested in receiving them. The newsletter gave details of the kinds of services available to the blind. Many persons responded with requests for services.

Mr. Bridges stated that a blind services file has been worked out with their data processing department, i.e., all programs are being coded. The data processing department maintains a

filecard to keep information relating to the type of service furnished each blind person and the duration of such service. This enables the division to determine annually how many and which persons did not receive services during the year.

In Mr. Bridges' opinion, the division is not doing a good job of educating the ophthalmologist to refer blind persons to the register. This may be a problem that is common to other States. In an attempt to inform the ophthalmologist what the division was doing, the agency had an exhibit at the last meeting of the New Orleans Academy of Ophthalmology at which time various pamphlets of the division and various MRA statistical reports were made available. Some physicians showed considerable interest in the statistics of these reports. It is hoped that increased referrals may result. A similar exhibit was shown at the Mississippi and Louisiana Academy of Ophthalmology meeting at Biloxi, Miss. Miss Ford indicated that an estimate of the number of blind people in Louisiana and in the United States, as well as the major causes of blindness in Louisiana, were included in materials mailed to ophthalmologists in Louisiana. Of the physicians that replied, at least half asked for additional statistics. This indicated an interest in data of this type. Miss Ford stated that there was some delay in sending coded forms to Bethesda because of the delay in receiving the new codes. She indicated, however, that many of their coding problems were being resolved by the new codes.

MASSACHUSETTS: Mr. Mungovan pointed out that in his State the problems have been related to the reporting of race and age of the blind and the discipline of examiner. Race has never been reported in the past because it was not considered necessary by the division. It was assumed that the discipline was so predominantly "ophthalmologist" that it was not necessary to report it. However, to conform to MRA standards, a start was made to record this information. The system has been gradually improved so that the needed information would be forthcoming. As soon as a case is registered, an acknowledgment is sent to the physician. Another letter, enclosing an information pamphlet, is sent to the registrant indicating that shortly he would be contacted by somebody from the division. Within a few weeks, the registrant is contacted by telephone first to make an appointment for a visit from a division staff member. If the registrant refuses to see such a staff person, no further attempt is made. If the reply is affirmative the visit is made.

He mentioned that, with the change in system, a statistical card is started at the point of registration with only the barest information. At the same time a face sheet is completed with the information obtained from the eye report. The face sheet is routed through the division to a fieldworker who makes the initial contact with the registrant and completes the face sheet with information on race, age, and any data left off the eye report form by the physician. The face sheet is then returned to the statistical clerk for processing. In Mr. Mungovan's opinion the new system should improve the quality of the statistics. In updating, a post card is sent out late in the year to every person with whom contact had not occurred that year. Through nondelivery of mail, it is learned that certain registrants have moved, or have died, or should be taken off the register.

In order to keep the ophthalmologist interested in reporting, a short abstract with a few high points of the MRA annual statistical report is sent to him. The actual MRA statistical report is sent if requested. Mr. Mungovan stated that at a recent meeting of the New England Ohpthalmological Society he learned that Massachusetts ophthalmologists, in general, do not report a person who is legally blind with an operable condition, such as cataract, if he is going to undergo surgery in the near future. It seems that the ophthalmologists do not report such cases to the Division of the Blind because they are not aware of the fact that the division would furnish any of the costs of rehabilitation and of the medical services. Mr. Mungovan stated that when the operating physician is paid by a prepayment plan or by the patient or where the physician performs the operation or service gratis, the patients often are not reported. Mr. Mungovan was uncertain as to whether such a patient should be considered blind if it

is a temporary condition which can be removed by surgery.

Although excellent relationships exist between the ophthalmologists and the division, in general, they do not seem to be aware that payment by the Vocational Rehabilitation Administration, through the division, would be permitted for hospital and surgical fees for this type of operation. In closing, Mr. Mungovan indicated his hope that ultimately he would have a larger statistical staff to keep up with the work.

NEW HAMPSHIRE: Mr. Camp stated that progress had been made during the past year despite the fact that his agency lost their registrar who had been on staff for 25 years and despite the fact that their medical-social work consultant had been transferred to other work in the department. During the year the New Hampshire blindness register was put on IBM cards. He indicated that dealing with the data processing people and their scheduling problems was a completely new experience for his agency. Having gone through the difficult period of conversion, he was optimistic about the future.

Some tangible progress already has been made in the area of updating as a result of conversion to IBM. For instance, the annual procedure of sending a letter to each town clerk listing the known blind in that town and asking the clerk to add to or subtract from it has been expedited considerably. The conversion has produced a machine listing of the 1,125 persons on the register. This permitted a followup on the persons who were not getting services. The result was that a lot of deadwood was cleared out of the register. There is also the cold realization that just knowing that there are 1,125 persons on the register does not mean that very much is being done for them. It has pointed up the fact that a staff is needed to get to these people and to service them. Although the register has been brought up to date, the agency is in a transitional stage and has not, as yet, realized all the good results it hopes it will realize from it. One of his unsolved problems is concerned with the people who do not come within the legal definition of blindness. In his opinion the New Hampshire Services to the Blind would sooner or later become a unit for the blind and visually handicapped. The visually handicapped, even though not legally blind, need services. It was his hope that some day the definition of the legally blind would include these people.

NEW JERSEY: In Mr. Kohn's opinion, New Jersey has about the same problems mentioned by representatives of other States. The new classification system of causes of severe vision impairment and blindness was found to be thorough, also quite complex. He wondered whether or not there might be an opportunity for a training session for the registrars and others that were involved in classification. With respect to updating, the procedures are much like those employed in other States, using a letter, however, instead of a post card. An attempt is made to reach about half of the register every second year in this letter which is sent to those not having services during the past year.

Mr. Kohn mentioned that a letter was sent to some 3,700 registrants who were approaching their 65th birthdays to remind them of the deadline on medicare applications. This resulted in about 600 letters being returned because of "unable to locate," "deceased," "moved," or "no address." The agency was thus able to effect a bit of housecleaning at the same time that it sent an informational item out to a particular group of registrants. The annual statistical reports of the MRA have been made available to ophthalmologists throughout the State. Accompanying the statistical report is a letter. An attempt is made to direct the letter to some aspects that might be of interest to the ophthalmologists. These aspects have varied from year to year. At the same time the agency did a digest of their own statistical information and made it available for public relations purposes to the board of the New Jersey Commission for the Blind and to other high level groups in the State.

During the process of feedback, a civil rights question was raised as to why the agency referred to race in its statistics. Mr. Kohn stated that the item of race was important, not in a discriminating manner, but rather as identifying information needed for medical

and research purposes, particularly with respect to (1) any relationships between eye conditions and racial status and (2) making sure that nonwhites, as well as whites, were receiving the services needed and requested. The matter was referred right up to the New Jersey State Board of Control. But nothing further came of it. Mr. Kohn mentioned that at least one Federal department has recommended that information on race be put back on applications for employment in the department after having had this information removed in the past.

Mr. Kohn also suggested considering the possibility of incorporating some of the data emerging from the MRA into a format suitable for use in the teaching of ophthalmology. In his opinion, this would create a needed link between organized ophthalmology and State blindness agencies. He also suggested the possibility of collecting data on other medical conditions in addition to ophthalmological diagnoses because many clients are multihandicapped. He indicated that medical consultants are increasingly urging the compilation of separate statistics on these added medical disabilities. Such compilation would add to the value of the statistics being accumulated. Mrs. Tomasulo mentioned that she had found the quality control program of the Biometrics Branch, NINDB, extremely helpful in the coding of eye reports.

NEW MEXICO: This State, according to Mr. Hebbeln, has made considerable progress, adding 179 persons to the register and removing 456 persons. At the beginning of the past year, the register had almost 2,900 names. At the end of the year it contained a little over 2,600 names. This was due very largely to "cleaning up" the unknowns and removing those names from the register that should be removed. Another factor was the eye restoration program which accounted for quite a number of restoration cases.

The degree of cooperation given by the ophthalmologist varies from region to region within the State. A problem that the agency has had for years has been the simplification of the forms being utilized. During the past 10 years, with the assistance of the supervising ophthalmologist, the eye-report form has been revised four or five times. It does not appear that it can be simplified any further. The form has two objectives: (1) provide a means for reporting, and (2) provide a means whereby the caseworker may know what is going on. There is also a simplified form of reporting for the ophthalmologist, if he cares to use it, which is referred to as the progress report form. However, the results from use of this form have been somewhat unhappy because, without some designation as to what the agency wants to know about the client, the ophthalmologist puts down whatever happens to occur to him. What he records does not always fit the agency's needs.

The division has suggested that the opthalmologists use the same report form for the initial examination, and then enter on the same type of form whatever progress information is needed. There is room for remarks on the form. If the ophthalmologists went along, it would also be easier for the agency to work with it. Although considerable ground has been covered, Mr. Hebbeln did not feel that all the blind in the State have been found.

NORTH CAROLINA: Miss Anderson emphasized that, in her opinion, the most sustaining and reassuring thing which has happened to the North Carolina Commission for the Blind is that the agency now has a full-time registrar instead of a part-time one. She indicated that the agency was getting more refined and valid data as time went on and as procedures sharpened up. In addition to the State Commission for the Blind staff, 100 county welfare directors, caseworkers, and their staffs are participating in gathering data on blind people. There are many administrative uses of register data.

In June 1965 a mass referral was made to the Social Security Administration of all persons 65 years of age or over for the new medicare program. It is expected that information on these persons will be fed back to the Commission by the Social Security Administration.

The North Carolina legislature has shown an interest in accidents as a cause of blindness. It has requested data on the number of persons losing their vision from BB guns. A study has

been under way on services to aged blind in their homes. A study of discipline of examiner as shown on reports in North Carolina revealed that the great majority of those certified as legally blind were examined by ophthalmologists. There were only about 18 examinations by optometrists last year. Although the eye-report form has been changed somewhat, all the MRA requirements were retained. However, since the physicians wanted space for remarks and prescriptions, this was added. There is now one eye report form for physicians and one for optometrists.

Miss Anderson stated that the agency will go into Title 19 of the new medicare program in fiscal 1967. It is expected to be very sustaining insofar as the register is concerned. Furthermore, the agency also will go into Title 1 of the Elementary and Secondary Education Act jointly with the State Department of Public Instruction, State Department of Mental Health, State Board of Health, North Carolina Medical Society, North Carolina Dental Society, and North Carolina Nursing Society which will cover all children from 5 through 17 years of age. From Miss Anderson's viewpoint one of the interesting things is the fact that the ophthalmologists are getting quite excited now about blindness statistics. They appear anxious to secure statistics on the reported prevalence of different blinding conditions in the State.

OREGON: Mr. Stocker stated that, prior to his interest in joining MRA, his agency had maintained a roster not only of blind persons, but also of those persons who had conditions which would ultimately lead to blindness if proper medical services were not provided for them. As a result of being admitted to MRA, the agency weeded out the nonlegally blind for statistical reporting purposes.

As of the end of 1965 the Oregon blindness register had 2,333 persons. During the calendar year 1965 there were 479 additions to, and 310 removals from, the register. The updating of the register is started right after Labor Day with a mailout of a stamped, self-addressed letter to everybody on the register. Some 2,300 letters were mailed in 1965 and about 1,700 replies were received. According to Mr. Stocker, one of the factors responsible for this high percent of return replies was the high percent of registrants in Oregon using talking books. In this regard, Oregon ranks second only to Vermont.

Approximately 68 percent of referrals to the register came from ophthalmologists. A few were referred by optometrists, but these persons then were sent to ophthalmologists for examination and report. Every attempt is made to have the examination made by a board-certified man. Even the older cases on the register are being reexamined by board-certified men.

The Commission for the Blind sends the MRA annual statistical reports to every ophthalmologist, EENT man, and optometrist in the State. Mr. Stocker mentioned an attempt is made to get acquainted with every new ophthalmologist in the State in order to establish good rapport. The whole program of the commission is explained to them.

The organizational structure of the commission is such that cooperation between State departments is facilitated. The commission includes five departmental and division heads as ex officio members, in addition to four lay members. The Department of Public Welfare sends to the commission each month lists of (1) all persons on aid-to-the-blind assistance, (2) new applications for such assistance, and (3) those who have been removed. These lists are compared with the names on the blindness register and appropriate changes made where necessary. The same type of working relationship is maintained with the Department of Education, particularly as it concerns special educational services, and with the Oregon State School for the Blind.

Mr. Stocker indicated his belief that the register is missing a good number of blind persons who are in State mental hospitals, schools for the retarded, etc. It was his opinion that there are probably 90 blind persons in such schools. He has brought this problem to the attention of the University of Oregon Medical School to determine whether the school would be interested in undertaking the ophthalmological examination of inmates of schools for the retarded. He hopes that this could be worked out in the next year or two. In State mental

hospitals, according to Mr. Stocker, were a number of blind patients and probably some of these could have their sight restored.

Mrs. Sokolow stated that it had not been possible to get much information from the Department of Public Welfare as to what would be provided to the blind by Medicare and how it would be provided. As a result the commission was in a position of not knowing how it could dovetail its services to meet those of Medicare. She was of the belief, as expressed by Miss Blase of Kansas, that a problem of securing reporting from physicians would arise when the Department of Public Welfare and the Social Security Administration take over assistance in the restoration of vision.

RHODE ISLAND: Mr. D'Andrea stated that in 1965 there were 92 new additions to, and 65 removals from, the register. The new additions represented a sizable increase over the number of the previous year. The number on the register as of the end of 1965 was 1,097 as compared to 1,065 at the end of 1964. The responsibility for coding has gradually evolved from placement upon two unit supervisors to placement directly into the hands of the general medical and ophthalmological consultants. The regular consultation form which had been used for many years has been modified to include the coding data itself and, thus, lends itself to the overall coding function that follows later.

Physicians at the time of consultation, and as they review each case, indicate on their forms such factors as visual acuity, site, etiology, type and affection, secondary disabilities, etc. An assistant registrar has been assigned to handle many of the detailed functions within the MRA system and to act as a liaison between coders, registrar, and others involved in the coding process. Consultation forms containing raw data are submitted to the assistant registrar who then applies the proper code numbers and insures that all other data for each register card has been properly and completely coded. The registrar continues to coordinate the overall MRA program within the agency concentrating efforts more intensively in the areas of status changes, removals, and pending cases. The registrar also serves as liaison for the agency with research and IBM units of the department in which tabulations and data runs are made. This system permits more accurate judgment in relation to decisions concerning factors which must correspond with those desired under MRA standards. The result has been a greater interest in, and understanding of, the meaning, goals, and objectives of MRA by agency staff who are present at each consultation.

Mr. D'Andrea mentioned that plans are under way to attempt to develop a master file plan which would include a register representing all the legally blind and all other referrals with severe visual impairments, in lieu of the current index file which has been used hitherto as a pilot file to identify those who are or are not registered with MRA. A number of problems have presented themselves in this connection but these were being worked out.

Interruptions in workflow due to limited staff, organizational redesign, and a variety of Federal requests have impeded agency efforts to concentrate on the further development of the MRA program. Mr. D'Andrea was convinced, however, that the reorganization of the system and method for coding within his agency during the past year had resulted in a much smoother functioning program, and it is expected that statistical results for 1966 will surpass those for the past year.

The agency has felt that a better job could be done in updating the register. Unfortunately, because of staff shrinkage and lack of time, not as much has been done as desired. However, plans are being built into the MRA program structure itself to permit an ongoing check on the register. As in the case of New Jersey, nondelivery of letters about Medicare to the registrants from the Division of Services for the Blind because of "change of address," "deceased," etc., was used to help in updating the register.

Efforts have been concentrated to inform and educate Rhode Island ophthalmologists to the general program of Services for the Blind, including the MRA program.

Mr. D'Andrea noted that a bill was introduced into the Rhode Island legislature during the last session to permit reporting of all legally blind persons in the State to the division. It is

not a mandatory reporting bill but contains provisions for reporting blind persons within 30 days. There are no penalty provisions but there are provisions to prevent misuse of confidential information. He stated that he has met with a number of ophthalmologists and gained their understanding and support for the bill. In this way he succeeded in letting them know better what services existed in the State for blind persons.

In concluding, Mr. D'Andrea urged that NINDB make available to participating States matching funds for the purpose of developing statistical research positions within each agency, in order to enable those agencies to focus and intensify their efforts on behalf of the MRA program. He felt certain that State legislatures could be convinced of the necessity of building in specific positions that would enhance the agency programs to a greater degree than at present. Setting up such positions was preferable to taking staff away from some of their assigned duties and giving them MRA functions. In his opinion the MRA program was important enough to have individuals devote full time to it. He also recommended that, if possible, NINDB produce the MRA annual statistical report as soon as possible following the close of the calendar year.

SOUTH DAKOTA: Mr. Reaves stated that the field counselors and office staff have worked hard in obtaining information concerning the blind in South Dakota in order to keep the register up to date. In November 1965 the Service to the Blind and Visually Handicapped began the process of updating the information on the register. To date there are only a few registrants that it has not been possible to contact in some manner. A card-type questionnaire was mailed to each registrant. When a blind person did not return the card, contact was made with the county welfare office in the county where the person last resided. In most cases it was possible to obtain correct information in this way. Since the county welfare offices have been notified of the agency interest in registering all blind persons, most of the counties have been very cooperative in advising the agency of information which serves that interest.

However, there is a problem in getting information, especially eye information, on the Indians who reside on the reservations. Due to an epidemic of trachoma on the reservations years ago, a large percent of South Dakota's blind citizens are Indians. There is also the problem introduced when the same Indian is registered twice because of the fact that most Indians have two words for their last names, and because of their occasionally dropping one or the other of the two words in giving their names. Thus, an Indian may at one time be registered with one of the two words in his last name and then be registered also with the other of the two words. It is also a problem to decide which name should remain in the register since both names are certain to be re-referred to the agency.

The ophthalmologists in South Dakota are one of the most cooperative groups in helping the agency to maintain a proper register. The registrar is now in the process of coding all new registrants since January 1, 1966, using the new coding system.

UTAH: Mr. Perry indicated that although Utah had met the requirements for acceptance into MRA, his agency was not yet completely satisfied with its own performance. Prior to its interest in MRA, his agency had a roster of blind individuals, but in most cases it did not contain eye information and other data needed for a satisfactory register. All of the agency staff have cooperated in updating the register. The ophthalmologists in Utah were not responsible for referring many blind persons prior to the introduction of the MRA project in the State. However, since that project started they have become very interested and are very cooperative. Mr. Perry believed that one of the reasons might be the fact that at the start of the project an ophthalmologist was hired by the agency as a consultant, and he has been able to build up some splendid relationships for the agency.

Mr. Perry mentioned that many ophthalmologists had recently complained about the length and complexity of the NSPB eye report form. They appointed a committee of their own to try to work out a new form that would give the agency the information needed and

that they felt they could live with. Mr. Perry stated that the advice of the Biometrics Branch, NINDB, would be sought before any changes in the form were accepted.

Everybody on the agency staff, and particularly the fieldworkers, were very MRA-conscious and, in return, the staff has found the information available in the file to be very valuable in their programs. One of the problems has been and will continue to be to try to find those individuals that are known to have been missed. This program of trying to find missed individuals has been applied in nursing homes and has turned up many presumed blind persons. However, this creates the additional problem of getting an ophthalmologist's report on such persons. The problem was solved in part by hiring a young ophthalmologist to go into some of the larger nursing homes and do examinations for the agency. Mr. Perry indicated that it will be necessary to develop a better rapport with, and a better system for getting referrals from, institutions for the mentally retarded and mentally ill in the State.

VERMONT: Miss Cole remarked that she was continually more and more impressed by the potential use of the register for program planning and as an aid in the provision of services. As an example, she stated that recently the statistical data proved very valuable in showing several optometrists that only about 2 percent of the referrals were coming from optometrists. Another example was in the rehabilitation program where it was felt that perhaps the agency was not reaching all the persons in the working age group that it should. As a result, the register punchcards were sorted by age levels and a determination made of how many persons in the working age group were in the rehabilitation program.

The register also has been used to find out which registrants were eligible for certain social security benefits of which they were unaware. Data from the register have provided the agency with useful trend data. For instance, a review of the data has shown that there is no longer a preponderance of newly registered female blind. Current figures indicate about as many new male as new female reported cases annually. There also appears to be evidence of more people in the middle-aged category becoming blind and of a drop in the old-age category. With respect to trends in etiology, diabetes as a cause of blindness is continuing to increase while the category of general diseases is decreasing.

Miss Cole stressed that she was continuing her practice of getting out annually to the ophthalmologists summaries of the statistical data, emphasizing important points. The agency knows that some ophthalmologists do not refer their patients to it while others are very good about doing so. She is anxious to improve relationships with some of the ophthalmologists, to find out how many patients are not being referred, and for what reasons. An effort is still under way to get the agency's eye report form used statewide. It is obvious that some other agencies in rehabilitation are using a different eye form. The use of one form would solve some of the reporting physician's problems.

VIRGINIA: Mr. Coppage commented that first additions to Virginia's MRA register in 1965 increased 30 percent over 1964. Over 94 percent of all first additions were examined by ophthalmologists or EENT specialists. The total number of registrants as of December 31, 1965, was 5,306—an increase of 551, or 11.9 percent over 1964.

The agency's organizational structure has been both an asset and liability in regard to maintaining the MRA register. It is in a unique position of being one of four States that supervises the Aid to the Blind (AB) Public Assistance Program apart from the State Welfare Department. All new recipients, and the approved eye reports, are immediately submitted to the agency's MRA section. This is definitely an asset for the MRA program.

In addition to the AB department, there are four departments submitting MRA data. These departments include rehabilitation, home teaching, talking book, and education services. Since it did not have a central file, the agency was confronted with duplication of new additions, which resulted in an unnecessary workload. Now that the register is up to date, it is used as a central locator file by all departments.

Whenever a department receives a referral, the MRA register is checked to determine (1) if the new referral is already on the register; (2) if so, what other department(s) have rendered services, and (3) if there is an approved eye report on this individual.

Up to this point the agency has been adding to, and removing from, the register only those persons referred to it. This year it is planned to go outside the agency in order to locate those persons who are legally blind (and unknown to the agency), not just to add their names to the MRA register, but to offer services.

The Biometrics Branch, NINDB, will prepare tabulations by county and city from each MRA State's 1965 IBM cards. This additional data will be most beneficial to the agency in making decisions in regard to which localities to survey in order to ascertain the true prevalence of blindness; what areas of the State reveal the highest and lowest incidence and prevalence; and where efforts should be concentrated in locating new additions for the register. It is believed that this conference provides an ideal place for the exchange of information and helpful solutions to like problems.

While some progress certainly had been made in the past year, there were still quite a few problems to solve. One step in that progress had been to secure a director of research and statistics for the agency. A major problem was to locate and identify all of the blind persons in the State who were unknown to the agency, let alone registered. Although his agency now had all of the names and information on blind persons being served by agencies within the State, there were apparently many blind persons who were not receiving any services from any agency and who had not been reported despite the State mandatory reporting law. Mr. Coppage stated that an approach to a solution of this problem would be taken in the near future when a public information officer is added to the staff.

IV. PROGRESS IN SELECTED NONMODEL REPORTING AREA STATES DURING 1965

DISTRICT OF COLUMBIA: Mr. Gambaro stated that during the past year all of the deadwood in the register had been removed. The register now contains over 1,300 names of persons with a current eye report, known to reside in the District. He mentioned some of the problems encountered when an agency is involved in setting up a register from scratch. Forms for reporting were designed or were modified from those used in other States. At the same time a system had to be designed for getting agencies to report automatically. It was Mr. Gambaro's belief that his agency would be able to submit accurate information to the Biometrics Branch, NINDB, by February 15, 1967, and thus be able to join MRA. He estimated that there would be about 1,900 names on the District register by the fall of 1966, which was somewhat short of the estimated blindness prevalence for the District. The difference is not due, in his opinion, to a faulty estimate but to the fact that certain ophthalmologists may not report their cases. He felt that a reporting law is essential since it prevents a lawsuit against the ophthalmologist for revealing privileged information.

An attempt has been made to get a register law enacted by the Congress. Such a bill has been introduced, but it has not been acted on as yet. As an indication of progress made to date, Mr. Gambaro pointed to the fact that the agency has a full-time registrar, a professional position, instead of a statistical clerk position. He recommended, based on his agency's experience, that (1) a State starting a register from scratch should consider a reporting law simultaneously because, in his opinion, it would be almost impossible to get the necessary information from the ophthalmologists otherwise; (2) personnel standards should be set up by NINDB, which would then be in a position to help support the justification for adequate personnel; (3) more direct help is needed from NINDB in the process of establishing a register and more staff time should be available from NINDB, possibly through increase of Biometrics Branch staff. More direct involvement of NINDB is needed in view of the fact that NINDB has an overview of the problems. The NINDB could act as a clearinghouse and make available the experience of other States to those starting fresh in developing a register; (4) the NINDB should attempt to get agreement among Federal agencies with blindness

programs in the standardization of eye-report forms, codes for causes of severe vision impairment and blindness, etc. This would ease the burden on State agencies. In his opinion, the NSPB eye-report form was a good one and ought to be used. He suggested that more effort be made to bring about an acceptance and adoption of this form so that agencies could report to one another without having to transfer and translate a lot of information.

GEORGIA: Mrs Curtin stated that the Georgia Services for the Blind became interested in a register about 2 years ago and began to build one from the ground up. Prior to that time, there had not been even a listing of blind persons available in Georgia. A start was made by getting copies of some 4,000 to 5,000 eye reports from the State Department of Family and Children Services of blind persons receiving aid-to-the-blind assistance.

Additional social and other information needed to compile the register was secured from the individual counties concerned. The register project is sponsored by the Community Services for the Blind in Atlanta in cooperation with the Vocational Rehabilitation Division of the State Department of Education from which agency data on about 1,100 vocational rehabilitation cases were secured. It is hoped to go back into all the old case records and pick up all the blind on whom there is some information and who are known to be alive and in the State.

Mrs. Curtin indicated that her agency has worked through all the State agencies—The Health Department, the Department of Education and its special classes in the public schools for blind children as well as its school for the blind—and has secured about 300 reports as a result, of which some 200 are blind students currently enrolled at the school for the blind in Macon. Lists of blind persons receiving braille books, talking books, and talking book machines were secured from the Georgia Library for the Blind. Social casework information on 155 presumably legally blind persons was received from the school for the mentally retarded. Adequate medical information was not available on these cases. Because the persons were mentally retarded, accurate visual examinations were difficult, if not impossible, to make.

The agency's work with the ophthalmologists has not produced the hoped-for results. The ophthalmologists were contacted by mail and were sent brochures and statistical reports of the MRA. Attempts are under way to set up small meetings with the ophthalmologists and talk about the register to them. Mrs. Curtin noted that the ophthalmologists seemed preoccupied mainly, as judged by the questions they asked, with the value of the register in getting to the patient. Apparently, at present, answers concerned with the medical research and community service factors did not seem to satisfy them.

According to Mrs. Curtin about 3,200 cases have already been coded for IBM punching, but this does not include coding for cause of blindness. When the new Index was recently received from NINDB, coding on cause was started. One of the things that is being incorporated into the register process is an updating procedure along the lines of cycle billing. By this method, updating is an ongoing project throughout the year.

Mrs. Curtin mentioned that some thought has been given to the advisability of changing the name from the Georgia Register of the Blind to the Georgia Register of the Visually Handicapped. A number of physicians objected to the word "blind" because some of the patients preferred not to be so designated. Also it seemed that some ophthalmologists were hesitant to give the register confidential information on the grounds of their possibly being sued. She indicated her interest in learning that a compulsory reporting law would protect the physicians from such liability.

MARYLAND: Mr. Delaney noted that Maryland has never had a register that utilized MRA standards. During the past year a number of preliminary steps were taken to establish a statewide register of all legally blind persons. Since the State Department of Education is the focal point for all service programs for the blind, with the exception of public welfare, it was considered that this would be the most logical department to undertake the establishment and maintenance of a register. A resolution to that effect was adopted by the State Board of Education in July 1965. The Division

of Vocational Rehabilitation of that department was authorized to undertake the project since it has a network of regional and local offices throughout the State and has close working relationships with all public and private agencies in the fields of health, education, and welfare, as well as with ophthalmologists, optometrists, eye clinics, and other groups interested in the visually handicapped. Mr. Delaney mentioned that in the beginning, at least, reporting would be on a voluntary basis since some opposition was anticipated to mandatory reporting.

Following a meeting held at the State Department of Education in October 1965, with staff of the Biometrics Branch, NINDB, at which time plans for development of an MRA register were outlined, letters were sent by the division to other State departments and to private agencies to solicit their support and, if possible, to secure their endorsement of the project in writing. A favorable response was elicited from all persons and agencies. Only two agencies felt that mandatory reporting was necessary.

A resolution was introduced in the State legislature which, in essence, endorsed the State Board of Education resolution. Since that time all possible referral agencies have been contacted. It has been determined that these agencies know of some 10,317 legally blind persons. Contractual assistance from NINDB will enable the agency to begin work on developing the register about July 1, 1966. NEW YORK: Mr. Friedensohn indicated some of the progress made to date in bringing the New York blindness register up to MRA standards. Case folders of 36,701 legally blind persons out of a total of 40,000 such persons have been reviewed. After the review is completed, efforts will be made to contact the registrants to determine whether they are still blind, alive, and residents of the State. By virtue of the temporary nature of the staff engaged under the NINDB contract to update the register, Mr. Friedensohn indicated that the agency's experience has been to lose staff almost as soon as they are trained.

One of the problems dealing with reporting of the blind in New York is concerned with the fact that the definition of blindness used in the State includes a clause which makes medical diagnosis part of the definition. The only reports now accepted and classified are from ophthalmologists plus some from general practitioners where the diagnosis is one that the general practitioner can make. An attempt is being made to change the definition which would make it possible to accept reports from optometrists. His agency is making its good offices available to representatives of the ophthalmological and optometric professions at the State level so that they may get together periodically to try to iron out some of their difficulties.

Mr. Friedensohn mentioned a study undertaken by a New York City voluntary association to determine reasons for the lag between the time of diagnosis as legally blind and the beginning of services to the legally blind in New York State. One of the findings indicated that a high percent of persons so diagnosed felt that they still had usable vision and, therefore, were not blind. Hence, they saw no need to go to an agency for the blind. These results constituted one of the reasons for a recent New York State law amending the commission's name.

Mr. Friedensohn suggested that, if possible, changes in MRA procedures be kept to a minimum. He indicated that every time a change is made, his agency had to go through 40,000 cases to make the change and that this was difficult to do, even electronically. It has been the experience of the commission that the intake of newly reported blind persons keeps on increasing annually. Last year's intake was 3,200 cases as compared to 2,700 cases the year before that. The agency is trying to find out the reason for this by analyzing where the new intake came from, the major age groups, causes of blindness, etc. This continuing increase is causing some concern to the agency. It was Mr. Friedensohn's opinion that Title 19 legislation in New York, by providing the people with the opportunity to get medical services far sooner than they previously have gotten them, should reduce the number of cases of blindness and should provide new knowledge.

V. ACTIVITIES RELATING TO VISION IMPAIRMENT PERFORMED BY THE BIOMETRICS BRANCH, NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND BLINDNESS, DURING 1965

a. ASSISTANCE TO STATES AND SPECIAL ACTIVITIES RELATING TO THE MODEL REPORTING AREA

Irving D. Goldberg, Assistant Chief, Biometrics Branch, NINDB.

Mr. Goldberg presented a summary of the various activities of the Biometrics Branch related to the Model Reporting Area, including the technical and contractual assistance provided to member and nonmember States. There were visits, and technical assistance given, to the States under contract with the NINDB relative to their registers. Among the MRA States, New Hampshire and Oregon were under contract during the past year and successfully fulfilled their contracts by putting their registers on to punchcard systems. Among the non-MRA States, South Dakota and Utah fulfilled their contract obligations and requirements for admission to MRA. Three other non-MRA States, District of Columbia, Georgia, and New York are under contract and are well along in their endeavor to meet MRA membership requirements. It is hoped that all three States will achieve this goal by the end of 1966. Maryland has just undertaken contractual obligations to develop a register along MRA lines.

Visits were made to all MRA States during 1965 for purposes of assistance with the annual tabulations, resolution of problems, and consultative assistance regarding the MRA and regarding possible studies, etc. There were some visits by Mrs. Moorhead, Medical Record Librarian, Biometrics Branch, NINDB, to the States with regard to the quality control program on causes of severe vision impairment and blindness. Much correspondence between the States and the Biometrics Branch took place with reference to this program.

A number of non-MRA States expressed an interest in the MRA program. These States were Colorado, Michigan, North Dakota, and Texas.

Mr. Goldberg mentioned a proposal relating to both the MRA and the talking book program of the Library of Congress. The proposal stemming from discussion with Mr. Robert S. Bray, Chief, Division for the Blind, and his staff at the Library of Congress, is designed to permit the blindness register and the talking book program of the Library of Congress to be of benefit to each other.

The proposal is as follows: Since virtually all of the registers in the MRA program are on punchcard systems, and since they also employ a register number mechanism, it is possible to set up a system whereby the blindness registers and the talking book programs could be of mutual benefit. This would mean that the talking book program in a given State would have to have on punchcards the identity of all users of the talking books. The register number used in the various States could be incorporated on the talking book punchcards with the register numbers serving as a means of identification, thereby resolving many problems of confidentiality. The immediate aim would be to set up a demonstration project in one of the MRA States to see if this punchcard proposal tying in the library users with the registers on a matching basis would be feasible. One State in particular which was mentioned as a possible site for this demonstration project was Oregon.

The essential benefits of this proposal would be that the Library would learn of how many and which blind persons on the register were or were not receiving talking book services. Further, missing information on the records of the talking book program could be derived from the register information. Thus, it could also identify the demographic characteristics of talking book users and nonusers. Furthermore, the Library could determine crudely what proportion of the total blind population they are actually serving. As far as the State registers are concerned this system would enable the States to determine the identity of presumably blind persons receiving talking book services who are not known to the State registers and, hence, serve as a means for keeping the registers complete and up to date.

The amount of work involved in providing the information to the talking book program

and to the register program should not be much since the great bulk of the work to be done would be through mechanically matching the punchcards from both programs, and could be tied into the annual register updating activity each year.

DISCUSSION

Mr. Friedensohn indicated that, in his opinion, most States provide names to the regional library rather than vice versa. Mr. Goldberg mentioned the fact that a person on the blindness register who is also receiving talking books can be presumed to be blind and alive, thus, knowledge of talking book services is of help in updating the register. Mr. Friedensohn stated that going through the register and getting the list of active readers, some 10,000 persons, proved to be the single greatest help in updating his register.

b. QUALITY CONTROL

Helen B. Moorhead, Medical Record Librarian, Biometrics Branch, NINDB

Mrs. Moorhead presented to the participants a progress report dealing with the MRA quality control program. A start was made on this program in 1965 with the purpose of insuring that the statistics which are collected in the Model Reporting Area are uniform. If two persons independently code the same report for site/type of affection and etiology, differences may and do occur. It has been found that with many people in widely separated areas coding many reports from many different physicians, differences are certain to occur and these could be destructive of a main goal of the MRA.

When the quality control program is fully functioning, it is believed that it will be possible to collect cause-of-blindness statistics that will be comparable from any part of the country. Furthermore, it is also believed that the program would have teaching value and would be a means of helping inexperienced coders to learn how to classify causes of blindness. It has been determined that there are innumerable variations among physicians in reporting cause information, and that these variations can add considerable complexity to the task of the coder.

Mrs. Moorhead indicated that additional and better instructions were needed for the coder, and many of these have already been put into use. It has been determined that one of the major problems for the coder is not how to code but what to code. Frequently an eye report will show two or more conditions, and if the physician has not indicated which one is primarily responsible for vision impairment, the coder must determine, if possible, which of the several conditions was the first to cause severe vision impairment. That decision may have a profound effect on the statistics being collected.

Identifying the primary cause of blindness is not always a simple task. One step toward making it easier would be the adoption of a uniform eye report form by all MRA members. After considerable study of the problems involved in securing accurate information, the NSPB developed a physician's eye report form. This was especially designed to lead the physician to show which one of the several conditions that he is reporting is primarily responsible for the impairment of vision.

Not all States may be able to adopt the form in its entirety. Some information may be needed by a State that the form does not provide. However, if a State could incorporate in its own eye report form the cause-of-blindness section from the NSPB form, all of the MRA States would have a uniform basis for the reporting of this important information. It would then be possible to develop one instruction guide for coders and one reporting form for physicians that would apply equally in all States.

Many States are using the form or parts of it. It would be interesting to hear comments about it from the ophthalmologists using it and comments from the agencies as to the results obtained by its use.

Several thousand eye reports have reached the Biometrics Branch from MRA States and from those States preparing for membership. These reports have been reviewed and the results communicated to the coders in the States. The Biometrics Branch has been impressed and encouraged by their interest and conscientious efforts to give their States and the

MRA accurate information on the causes of visual impairment.

Mrs. Moorhead said she would assist the coders in any way possible and would try to improve service to the States by earlier reviews of report forms submitted as part of the quality control program. She was particularly anxious that the coders write to her if they had any questions pertaining to changes in the classification or index.

Dr. Goldstein appealed to the States represented at the Conference to assist Mrs. Moorhead in making the quality control program successful. He indicated that she literally is being asked to make decisions on causes of blindness and that such decisions do not belong to her. The decision belongs primarily to the ophthalmologist who must indicate what, in his opinion, is the primary cause. A good eye report form, one that would indicate that unique ocular condition that started the chain of events leading to blindness, would make it simple for the consulting ophthalmologist to arrive at the right classification. Thus, a good form would be a necessary first step.

The second step is the institution by the States of a good, comprehensive query system. Where incomplete, ambiguous, or inaccurate reports are received from the field, it is imperative that the ophthalmologist be queried for better information. Such a query system must be followed systematically if good cause statistics are to result. Otherwise, the problems are sent to the Biometrics Branch where it becomes almost an impossible job to decipher what the ophthalmologist had in mind.

c. RESEARCH ACTIVITIES

1. Study of Association Between Factors of Pregnancy, Labor, and Delivery, and the Occurrence of Blindness in Children

   Irving D. Goldberg, Assistant Chief, Biometrics Branch, NINDB.

Mr. Goldberg stated that the collection of data for the above study has been completed and analysis of the data almost finished. It is hoped that the report will be finished and submitted for publication in a scientific journal within the next few months. Some preliminary results are, however, available. There were two study objectives: (1) To determine whether mothers of blind children are characterized by an excess of selected disorders of pregnancy, labor, and delivery, as compared with mothers of the total population of live births surviving the neonatal period; (2) To study the distribution of birth weights of the blind children as compared with a control population. Somewhat less than 600 cases met the following 5 criteria: (*a*) They were born during the period 1948 through 1959; (*b*) They were classified "blind" by the New York State Commission for the Blind during the period 1948 through 1960; (*c*) The blindness was presumed to be due to unspecified prenatal factors, or of hereditary origin, or of unknown cause, as indicated in the records of the Commission; (*d*) They had to have birth certificates on file at the New York City or New York State Departments of Health; and (*e*) They had to be single-born and to have survived the neonatal period, i.e., the first 28 days of life.

The control group that was used was a stratified sample of 3 in every 1,000 recorded live births in New York State during the years 1948 through 1959, who also survived the neonatal period.

The cases and controls, thus, were drawn from the same period of years and represent similar populations in that respect. The information which was collected for both cases and controls included the items appearing on birth certificates, such as date and county of birth, sex of child, weight at birth, race of mother, age of mother, number of previous children, specific complications of pregnancy, specific complications of labor, operative procedures used, Rh factor, and presence or absence of congenital abnormality or birth injury. For the cases only, there was secured from the commission's records the cause of blindness by site/type and etiology and the year the child was classified blind.

The cases and controls were compared on the various items of information collected for both, including the reported frequency of occurrence of these items and distribution of such variables as birth weight and age of mother. Insofar as possible, different categories (type/site) of blindness were studied separately.

Mr. Goldberg indicated that he would briefly mention some of the findings to date that appear to be either statistically significant or appear otherwise to be of some importance and worth further study in depth. He cautioned, however, that this was a crude study insofar as it was based on birth certificate information which might not be particularly accurate. Although many of the medical items could not be expected to have much scientific reliability, they might furnish clues for further research in depth.

The data were divided into those referring to cases and controls in New York City and those in New York State exclusive of New York City (referred to as Upstate New York) because of some differences in the kinds of information appearing on the birth certificates and because of some differences in the composition of the respective populations (e.g., New York City has a greater population of Negroes or nonwhites than Upstate New York). Furthermore, New York City is totally urban. This, of course, is not true for Upstate New York.

Results for Upstate New York showed the mothers of cases to have a significantly greater number of prior stillbirths than would have been expected in the general population as defined by the controls. There were about three times as many prior stillbirths in mothers of cases as in mothers of controls. Both in New York City and in Upstate New York, there appeared to be about twice as many mothers among the case group who had one or more complications of pregnancy than expected among mothers of the general control population. This was statistically significant. With regard to specific complications of pregnancy, for both New York City and Upstate New York there was an appreciable excess over expectation in the number of mothers with preeclampsia. Thus, for the total study group this complication was reported in three times as many case mothers as expected. Mr. Goldberg emphasized, however, that complications of pregnancy represent one of the poorest items reported on the birth certificate. However, as a clue, it might be indicative of further study.

In Upstate New York there were about 30 percent more primiparae, i.e., women with no previous pregnancies resulting in a viable child, among the mothers of the cases than expected. Apparently, the type of blindness investigated in this study is a condition which may occur more frequently among first births.

Based on race of mother, it was found that the ratio of nonwhites to whites was more than 30 percent higher in the case group than expected. It is interesting to note that the MRA statistics by race show the reported incidence and prevalence rates of blindness for nonwhites to be greater than those for whites.

The data show, perhaps as to be expected, that significantly more of the case group than expected had a congenital abnormality reported on the birth certificate. The preponderance of the abnormalities reported in the case group related to the eye.

With respect to maternal age at time of delivery, there is some indication, at least in Upstate New York, that the young mothers (those under 20 years of age) and the older mothers (those 35 years or over) are high-risk groups with regard to blindness in their offspring, i.e., the proportions of mothers in these age groups in the case group was appreciably higher than the expected proportions based on the control group.

The one item to which most of the findings mentioned above appear to relate is birth weight. Prematurity is defined by many people as a birth weight under 2,501 grams, i.e., under about 5½ pounds. There was a statistically significant difference between the cases and controls in this respect, both for New York City and Upstate New York. For the total study group there were about three times as many prematures among the cases as the control expectation. The excess of observed and expected was particularly pronounced for very small babies (i.e., under 1,501 grams) and the difference diminished with increasing birth weight. Proportionately more cases than expected were found in all birth weight groups through 3,000 grams after which the pattern reversed. As noted above the various findings are interrelated, that is birth weight is known to be associated with maternal age, parity, race, etc. The final analysis of these data is in progress.

This study could not have been undertaken without the cooperation of the New York State

Commission for the Blind and the New York City and New York State Health Departments. It reveals how a register may be used effectively for research.

2. Study of Attitudes, Awareness, and Performance of Blindness Reporting Sources

   Ronald L. Jacobson, Statistician, Biometrics Branch, NINDB.

This study is being conducted jointly by the American Foundation for the Blind and the Biometrics Branch, NINDB. The details regarding its objectives and study design are contained in the Proceedings of the Third and Fourth Annual Conferences of the Model Reporting Area for Blindness Statistics. The present status of the study is as follows: (1) Personal interviews have been obtained from all register agency directors and consulting ophthalmologists in 29 States that are either in MRA or have laws requiring them to maintain blindness registers; (2) Personal interviews have also been completed for a sample of ophthalmologists, EENT specialists, and optometrists in these 29 States; (3) All data for the study have been transferred to punchcards; and (4) Final corrections in the coding are now being made and proposed tables will soon be prepared.

3. Tonometric Surveys

   Ronald L. Jacobson, Statistician, Biometrics Branch, NINDB.

The Biometrics Branch is assisting Dr. J. Theodore Schwartz, Head, Section on Ophthalmic Field and Developmental Research, Epidemiology Branch, NINDB, in the collection and analysis of data obtained during their recent communitywide investigations of intraocular pressure. In an early study, described last year at the Fourth Annual Conference of the Model Reporting Area, 500 Italian-Americans were examined in Nesquehoning, Pa. Two additional surveys have now been completed, and ocular tensions are recorded for the American Indian populations of the Colorado River and Salt River Reservations in Arizona.

Elevated intraocular pressure is one of the cardinal signs of glaucoma and in these surveys three different methods were used to measure the intraocular pressure. In addition to the familiar and widely used Schiotz instrument, Goldman applanation tonometry was employed with the patient in both the sitting and the reclining position. In the last survey at Salt River, the Maklakov tonometer as modified by Posner and Inglima was also used. The data now collected will provide a comparison of the performance of those tonometers in common clinical use throughout the world. Direct comparison of the performance of instruments is possible on both an individual and population basis. The effect of postural change on the level of intraocular pressure and the interaction of these factors with changes in blood pressure corresponding to similar changes in posture are some of the ancillary investigations being conducted.

The Section on Ophthalmic Field and Developmental Research has been interested in undertaking these investigations in order to obtain background information which is needed to design full-scale investigations on the frequency of ocular hypertension among different populations. An important conclusion already derived from these surveys pertains to the question of reliability and comparability of various methods of tonometry. Significant differences were noted in the measurement of intraocular pressure by different tonometric techniques. Intermethod deviations are of sufficient magnitude as to throw doubt on the reliability of direct comparison of individual or population average tensions when these are obtained by the different methods. Further analysis will explore causes behind these discrepancies and attempt to derive methods of correction.

4. Study of Association of Perinatal Factors With Strabismus in Negro Children

   Dr. Hyman Goldstein, Chief, Biometrics Branch, NINDB.

This study, mentioned in the Proceedings of the Third and Fourth Annual Conferences of the Model Reporting Area for Blindness Statistics, was completed and a paper presented at the October 1965 meeting of the American Public Health Association. It is scheduled for publication in the Journal of the American Public Health Association in December 1966.

The objectives of the study were to determine: (1) whether the distribution of birth weights of Negro children with strabismus was different from that of Negro controls, and (2) whether the pregnancies of mothers of the children with strabismus were characterized by an excess of selected perinatal disorders. Strabismus, a highly prevalent condition in children is related to amblyopia ex anopsia, a potentially blinding condition, and may be related to psychological trauma. Little is known of its cause.

In the study, 406 Negro children with diagnosed strabismus, born in Maryland since 1950, were studied retrospectively. A birth certificate control was matched to each subject by race, sex, plurality, age of mother, hospital, and date of delivery. Children with other diagnosed neurological conditions were excluded from the case group. Data on the diagnoses of the strabismic children were obtained from eye clinics in Baltimore serving essentially similar Negro population groups. Only children with diagnoses of esotropia (convergent squint) or exotropia (divergent squint) were studied. All subjects and controls had been born in hospital wards—almost 90 percent in four Baltimore hospitals. Thus, the subjects and controls were relatively homogeneous in socioeconomic status and problems of bias usually inherent in differences among hospitals were reduced.

Steps were taken so that the physician who abstracted the information concerning the pregnancy from hospital records would not know whether the information related to a strabismic child or to a control.

The results were as follows: (1) The lower birth weights of the strabismic subjects were associated with shorter pregnancies. It was believed that the strabismic babies were immature rather than undersized. These children were not found to be undersized relative to control infants born after gestational periods of the same length. Strabismic infants weighed less even when gravidity was controlled, a result which suggests that strabismus is directly associated with birth weight; thus, a reduction in prematurity should result in lowered incidence of strabismus; (2) The mothers of strabismic children had no more complications of pregnancy and delivery than the control mothers. They were the women delivering premature infants without recognizable cause. They had suffered more previous pregnancy loss, such as abortion or stillbirth, than control mothers of similar gravidity; (3) A significantly higher proportion of strabismic infants than controls had major abnormalities at birth or shortly thereafter, especially respiratory conditions causing anoxia. A majority of the abnormalities among subjects and controls were those usually associated with prematurity, a finding that reemphasizes the importance of the relationship between prematurity and childhood morbidity.

VI. MODEL REPORTING AREA TABULATIONS—PROGRESS AND PLANS

a. REPORT OF PRELIMINARY TABULATIONS FOR 1965

Ronald L. Jacobson, Statistician, Biometrics Branch, NINDB.

(Note.—Due to the preliminary nature of the tabulations presented at the Conference, the presentation by Mr. Jacobson which follows is limited to the general aspects and implications of the 1965 preliminary tabulations. However, a final detailed report of the 1965 tabulations of the Model Reporting Area for Blindness Statistics will be published as a separate document.)

Mr. Jacobson first noted that the preliminary tabulations represented data which were submitted by the 14 Model Reporting Area States. He indicated that since Utah was in the process of completing its register during 1965, data on removals were not available. Thus, data for Utah would be confined to those tabulations relating to additions to the register during the year and total on the register at the end of the year. South Dakota, which was also in the process of completing its register during the year, was unable to provide data on additions to the register. Data for South Dakota would, therefore, include only those tabulations relating to total on the register at the end of the year and removals from the register during the year.

It was pointed out by Mr. Jacobson that data on causes of blindness were not included in his

report. He indicated that, as a result of the quality control program, data on cause of blindness were still in the process of being reviewed. Mr. Jacobson assured the conferees that the nine tables on causes of blindness would be published in the 1965 Statistical Report of the Model Reporting Area for Blindness Statistics.

Mr. Jacobson cautioned the conferees regarding their interpretation of the rate portions of the tables 2 and 20. He indicated that reliable estimates of the population of each MRA State for race, by age and sex for a noncensus year, are not available. As a result, the age-specific rates in the race portion of the table should be regarded as a crude representation and not necessarily as a reflection of the true reported incidence rates in that particular portion of the population.

The 17 tables presented were summarized by Mr. Jacobson as follows:

Table 1: Summary Data.

Tables 2–7: All additions to the register in 1965.

Tables 8–10: First additions to the register in 1965.

Tables 20–25: End-of-year total on the register.

Table 26: Register removals during the year.

The titles of the tables presented and discussed were as follows:

1. Summary table of first additions, readditions, removals, and end-of-year total on register: each MRA State and MRA total, 1965.
2. All additions to the register by race, sex, and age: MRA total, 1965. (Number and rate.)
3. All additions to register by race and sex: each MRA State and MRA total, 1965. (Number and rate.)
4. All additions to register by age: each MRA State and MRA total, 1965. (Number and rate).
5. All additions to register by degree of vision: each MRA State and MRA total, 1965. (Number and percent.)
6. All additions to register by race, sex, and degree of vision: MRA total, 1965. (Number and percent.)
7. All additions to register by age and degree of vision: MRA total, 1965. (Number and percent.)
8. First additions to register by age at onset: each MRA State and MRA total, 1965. (Number and percent.)
9. First additions to register by discipline of examiner: each MRA State and MRA total, 1965. (Number and percent.)
10. First additions to register by degree of vision and discipline of examiner: MRA total, 1965. (Number and percent.)

(11 through 19 on causes of blindness were not available.)

20. Total on register by race, sex, and age: MRA total, as of December 31, 1965. (Number and rate.)
21. Total on register by race and sex: each MRA State and MRA total, as of December 31, 1965. (Number and rate.)
22. Total on register by age: each MRA State and MRA total, as of December 31, 1965. (Number and rate.)
23. Total on register by degree of vision: each MRA State and MRA total, as of December 31, 1965. (Number and percent.)
24. Total on register by race, sex, and degree of vision: MRA total, as of December 31, 1965. (Number and percent.)
25. Total on register by age and degree of vision: MRA total as of December 31, 1965. (Number and percent.)
26. Removals from register by reason for removal: each MRA State and MRA total, 1965. (Number and percent.)

b. TABULATION PLANS FOR 1966 AND SUBSEQUENT YEARS

Irving D. Goldberg, Assistant Chief, Biometrics Branch, NINDB.

Mr. Goldberg stated that he was very gratified to hear Dr. Hurlin's comments regarding the accuracy of the statistics collected in the Model Reporting Area. It was pointed out by Mr. Goldberg that most of the emphasis of the Biometrics Branch has been placed in a solidly developing program. Later, as the program progressed, the emphasis has been directed at becoming more critical of what is being done. In his remarks Mr. Goldberg ex-

pressed his appreciation to Dr. Hurlin for giving his constructive criticism and stated that the next step would be to study how the quality of the statistics of the Model Reporting Area can be improved.

Mr. Goldberg commented briefly about the mechanical-type punchcard system which is in use in all but one of the 14 MRA States. He stated that the centralized use of the punchcards for preparation of annual tabulations appeared to be working very well. Not only does it permit a great flexibility in the kinds of regular and special tables that can be produced, but it provides an efficient method of preparing tables through use of computer facilities.

The annual punchcard editing procedures, as executed by each of the register agencies and by the Biometrics Branch preparatory to running the tabulations, have appeared to work very satisfactorily. It was indicated by Mr. Goldberg that the majority of errors are corrected by the register agencies as a result of their editing procedures before submitting the cards to the Biometrics Branch. Appreciation was expressed to the members of the Model Reporting Area for their cooperation in editing their punchcards.

In order to get the maximum information out of the MRA registers, Mr. Goldberg pointed out that several problems still exist and must be resolved. He stated that hereafter special attention would be given to these problems on a State-by-State basis in conjunction with the annual visits of the Biometrics Branch staff. One item of continual importance is concerned with the elimination of information indicated as "unknown." Although there has been a great improvement over the years since the beginning of the MRA, there still exist a few items in some States where, for a considerable number of registrants, the information for these items is indicated as unknown. Mr. Goldberg cited "date of onset of blindness" as being one item with the highest proportion of unknown information. Other items included age and race where much of the information was still unknown. It was stressed to the conferees that every effort should be made to follow up for any missing information. Perhaps the most important single item which should be followed up for complete and accurate information is cause of blindness.

Another problem mentioned by Mr. Goldberg was the matter of bookkeeping inaccuracies. Mr. Goldberg stated that one of the most important areas of concern to the Model Reporting Area is the fact that for several States the number of persons on the register at the end of a given year does not correspond to the register totals at the end of the following year, based on the number of additions to and removals from the register during the course of the following year. There is great variation in the number of bookkeeping errors among the States. This has ranged from apparently accurate bookkeeping during 1965 to an unexplained net loss of over 200 cases. A similar picture, perhaps even to a greater extent of error, was present in previous years as well. Such error makes it extremely difficult to evaluate information from year to year. It was explained by Mr. Goldberg that in the early years of the MRA special efforts were made to update various registers. As a result of such updating procedures many persons were removed from the register, so-called "deadwood," and no account was taken of these removals. Thus, the statistics from one year to the next did not correspond. However, in more recent years such an explanation could not be given. He again stressed the importance of accurate bookkeeping and added that inaccuracies of this nature in published material might cast doubt on the accuracy of all MRA statistics. It was pointed out to the conferees that the Biometrics Branch staff plans to discuss with each State agency on the next annual visit to the State the problem of bookkeeping inaccuracies.

Besides the set of tabulations which were discussed at the Conference by Mr. Jacobson, it was noted that the preparation of the cause-of-blindness tables had been delayed. The reason for this delay was an attempt to incorporate the benefits of the quality control program into the 1965 statistics. As soon as the quality control review has been completed of all 1965 cases, it will be possible to prepare tabulations which should then reflect a better degree of uniformity than would otherwise be possible.

Mr. Goldberg next described two special tabulations which will be prepared from the 1965 data later this year. Each of the States will receive a special tabulation for 1965 showing the first additions to the register, readditions to the register, and total on the register at the end of the year for each county by race and sex. Another special tabulation will show for each State the first additions, readditions, and total on the register by race, sex, and single years of age. Mr. Goldberg invited the conferees to make any suggestions they might have for special tabulations which could be prepared at the time the tabulations for the annual report are made.

With regard to plans for future years, Mr. Goldberg indicated that no major changes were anticipated in the annual tabulations. However, he did point out that one special tabulation will be requested for use in a special ongoing study. This table affects those removals from the register who are removed because they moved out of the State. It would be desirable to know the place to which these persons moved. For the purpose of facilitating the preparation of this tabulation at the end of the year, it would be well to indicate on the register cards the place to which such persons moved. Mr. Goldberg mentioned that it was planned to begin collecting this information on an annual basis in 1966.

The conferees were reminded by Mr. Goldberg of the basic plan of special tabulations for each of the 3 years around the upcoming census, which are 1969, 1970, and 1971. The census information will not only provide accurate population data for 1970 but will also permit recalculation of more accurate population estimates for the 1960 decade. This will allow the Biometric Branch to take the MRA statistics that it has been collecting since 1962 and produce rates in retrospect which can be interpreted as trend information. However, Mr. Goldberg emphasized that before information of this kind could be published, it must be determined that the MRA statistics are accurate and that bookkeeping errors are minimal.

Earlier in the Conference, Mr. McCollam had mentioned that the February 15 deadline for submitting punchcards to the Biometrics Branch for the annual MRA tabulations did not permit the States enough time. Mr. Goldberg reminded the conferees that this schedule had been established because most of the States could meet it, and because it allowed the Biometrics Branch enough time to tabulate data for presentation at the annual conference. He expressed some doubt regarding the availability of sufficient time for the Biometrics Branch to prepare the tables in time for the annual conference if the deadline were changed to a later date. He hoped that the register agencies would continue to try meeting this deadline.

With regard to reporting all known blind persons to the register, Mr. Goldberg commented on a remark in this connection made earlier by Mr. Mungovan. The following example was cited. If a person who is to be operated on for a cataract is blind, that individual should be reported to the register of the blind even though he might not be blind after the operation. Mr. Goldberg stressed the importance of registering such a person and then removing him from the register if he is no longer blind. This not only provides accurate incidence data but gives an indication of the extent to which measures are being taken to restore vision in the blind population.

VII. OTHER BUSINESS

Dr. Goldstein announced that Mr. H. Kenneth McCollam, director, Connecticut Board of Education and Services for the Blind had been elected to a 2-year term on the MRA Advisory Group, and that both Mr. Joseph Kohn, executive director, New Jersey Commission for the Blind and Miss Christine Anderson, supervisor of the Social Service Division, North Carolina Commission for the Blind, had each been elected for 1-year terms.

Dr. Goldstein mentioned the policy of alternating the places where annual conferences were to be held so that every other year the meeting would be held in Bethesda, Md. Thus, the 1967 meeting would be held there sometime in May.

Mr. Bridges invited the MRA to hold its 1968 Conference in New Orleans, La., indicating some of the features of that city that would appeal to participants. Mr. Stocker, under authorization from the Portland Cham-

ber of Commerce, cordially invited the MRA States to convene in Portland, Oreg., in 1968 and also mentioned a host of attractions to be found in that city. Dr. Goldstein indicated that it would not be possible to make a final recommendation until more is known about the Biometrics Branch budget for fiscal year 1968. He conveyed the thanks of the MRA States to Mr. Bridges and Mr. Stocker for their kind invitations.

Mr. McCollam expressed the appreciation of the MRA States and non-MRA States represented as well as all the other guests to Dr. Goldstein and his staff for arranging an excellent annual meeting.

Dr. Goldstein conveyed the thanks of the Model Reporting Area to the Massachusetts Division of the Blind for its cordial hospitality throughout the Conference.

In concluding, Dr. Goldstein invited comments from participants on suggestions for improving the annual meetings and for inclusion in next year's agenda.

The Conference adjourned at 12:25 p.m. on May 20, 1966.

APPENDIX A

Homocystinuria Screening Project

Victor A. McKusick, M.D.[1]

There is, in addition to and separate from the consideration of this specific project, dealing with screening for homocystinuria, perhaps a methodologic consideration as to what use can registers, such as those that you are concerned with, be put to in research on eye disease.

I think you are all aware that in this country in particular, with the infectious etiology falling off in importance, with nutritional etiology falling off in importance, hereditary factors in blindness have assumed, relatively speaking, much greater importance.

I would hesitate to estimate what proportion of blindness is mainly or at least in part genetically determined, but it must be a very significant proportion. The question is, I think, whether registers, such as you work with, can be used for research in this area.

There are two characteristics about the types of problems involved in genetic disorders of the eye that perhaps should be mentioned. One is that the individual disorders are rare, although in the aggregate they add up a significant body of disease. The second point derives from the fact that most of the studies that I have in mind have as their goals: (1) getting at the mode of inheritance of the particular condition, so that advice can be given to families; (2) getting at what the biochemical defect is in some of these hereditary disorders; (3) sorting out the different types of lesions.

These types of studies necessitate access to the individual patients. In other words, the lumped statistics will not suffice. One must have access to the individual families in order to assemble additional information. So the question boils down to how registers can be used for initial ascertainment of cases, while maintaining at the same time the confidentiality of the registry, avoiding infringements on the privacy of the patient, and maintaining the confidence of the physician who reports information to the registry.

You are perhaps aware that there is a condition called Marfan's syndrome in which the eye is affected with dislocation of the lens being the cardinal feature, in which there are skeletal features, with the patient being excessively tall as a rule, and in which there are other manifestations, including cardiac problems in some cases.

It has been found recently that some of the patients who simulate the true Marfan's syndrome have a distinct metabolic disorder which is called homocystinuria. It has this name because there is a substance, homocystine, which appears in the urine. This condition is readily diagnosed by identifying the substance in the urine of patients with dislocated lenses or suspected Marfan's syndrome through use of the cyanide-nitroprusside test.

This condition also has dislocation of the lenses and often severe myopia. The dislocation of the lenses is progressive. By age 10, all of the patients with homocystinuria probably have dislocation of the lenses. In addition they have skeletal problems, soft bones being a leading feature, and they have vascular problems, thrombotic in nature. They get arterial thrombosis, including coronary thrombosis and venous thrombosis.

About 2 years ago we mounted a wide survey of cases with dislocated lenses and or cases that were presumed to be Marfan's syndrome. We were able to conduct this survey, getting urine samples by mail. As a result we were able

[1] Professor of Medicine, The Johns Hopkins Hospital, Baltimore, Md.

to screen a fairly large series of cases of the categories mentioned.

The urine was screened at Johns Hopkins Hospital in Baltimore on patients in these diagnostic categories. The help and cooperation of many ophthalmologists and large ophthalmology centers throughout this country made this possible.

Thus far, we have screened at least 1 member of over 700 families in which there is at least 1 individual who answers the description that I mentioned. It turns out that 5 percent of nontraumatic dislocated lenses is on the basis of homocystinuria.

The uses to which data from families ascertained to have homocystinuria can be put are several: (1) To determine the precise mode of inheritance of this condition, and it proves to be inherited as a recessive disorder. Brothers and sisters are affected, but parents are normal, and as a rule when these individuals have children, they do not pass it on to their children; (2) to determine how prevalent this disease is. We realize that this is a minimal prevalence figure, and this is in fact the reason why we would like to cast our net more widely, if possible, through your help; (3) to determine whether some groups of particular ethnic extraction are more frequently affected than others. The data to date indicate that this is fairly homogeneous in its distribution through the many different types of extractions which are represented in Americans; and (4) to discover more about what the mechanism of the metabolic defect is and, potentially, to devise a treatment of this metabolic defect. The enzyme defect has been identified and it has many parallels to PKU (phenylketonuria) which you know is now amenable to treatment by dietary means.

Even though this is a genetic defect, the genetic defect is of such a type that these individuals don't metabolize the amino acid methionine properly. If the diet is adjusted properly to reduce the methionine intake, it appears that many of the features of the disease, including dislocated lenses, can be avoided.

I was going to show you some slides which give you some idea about the nature of the screening test, and show you some pedigrees and data that we have collected from our surveys thus far.

In over 700 families that we have screened, we have identified 35 families that have homocystinuria. Somewhat over 60 patients with homocystinuria are included in this series.

The method which I think could be used and the method which we have used in other somewhat parallel situations would be as follows: For the registry—this is one method that could be modified as seemed indicated—to inform the family that we at Johns Hopkins Hospital are conducting such a test on urine for purposes of studying eye problems, and ask if they would be willing to provide a urine sample. If the card is returned in the affirmative, then a plastic container would be mailed to the patient with postage for return to Baltimore for a testing.

If it would seem indicated, the physician who reported the case could be gotten into the system at some point. Perhaps the initial inquiry, initial invitation for cooperation, could be made to the physician and through the physician, or with his permission, then made to the family. I think that this illustrates the question about what use can be made of registries for the investigation of specific entities which require access to specific patient groups.

I could well imagine that someone would be interested in studying corneal dystrophy or studying congenital glaucoma and so on, and that your registries could be very valuable sources of material in scientific studies of this type.

DISCUSSION

Mr. Gambaro asked whether the determination that a blind person had homocystinuria would affect rehabilitation or the development of case services. Dr. McKusick replied that the dietary therapy of homocystinuria had not been entirely worked out as yet. It represented a promising area rather than an established method of management. However, he emphasized that it was important to be able to distinguish homocystinuria patients from those with Marfan's syndrome because of the thrombophlebitis and thrombotic accidents to which homocystinuria patients are subject. A

number of such patients have been placed on long-term anticoagulant therapy. In general, in medicine there is no substitute for an accurate diagnosis. The proposed screening program makes possible a desired differential diagnosis.

Mr. McCollam pointed out that if the register were to include cases above the legal definition of blindness, it would be possible to find more cases for screening purposes. Dr. McKusick indicated that of the approximately 60 cases of homocystinuria that have been picked up, probably only 5 to 10 of them might find their way to blindness registers with the blindness definition as it is.

In reply to a question from Miss McLaughlin as to whether dislocated lenses and other complications of homocystinuria could be prevented with treatment, Dr. McKusick stated that there appeared evidence that this was possible, but it was not an established fact as yet. There was every reason to think that dislocation of a lens is a progressive affair. This stemmed from the fact that dislocation of the lens was often not evident even with very competent eye examinations in such cases although myopia, not of severity enough to come within the definition of blindness, might be present in fairly marked degree. However, during the course of repeated examinations over a period of years, the dislocation of the lens appeared. The fact that the effects on the eyes might be progressive has a hopeful aspect because, if this is so, the metabolic defect can be controlled. There would be every reason to believe that dislocation might be prevented if therapy were instituted between the ages of 5 and 10 years.

There was further discussion as to how to identify the cases desired for screening by Dr. McKusick. Mr. D'Andrea inquired whether the prevalence rate for Marfan's syndrome in the population was known. In reply, Dr. McKusick stated that a rough estimate would indicate it occurred in about 1 case in every 20,000 births which would make it a fairly rare occurrence. However, it closely approximates the prevalence rate for the metabolic defect known as phenylketonuria (PKU). A question was raised by Miss Cole concerning the degree of association between screening for PKU and screening for homocystinuria. Dr. McKusick mentioned that a screening program for PKU in the newborn, already in existence at the Massachusetts General Hospital in Boston under the direction of Dr. Mary Efron, has homocystinuria screening built into it. He further added that, to his knowledge, the youngest patients that have been picked up have been about a year old. It was his opinion that anyone in whom the possibility of Marfan's syndrome is raised should have the homocystinuria test. Even if some should prove not to have homocystinuria, the wisest approach is to perform the test.

Dr. McKusick emphasized that cooperation by the State agencies with his program will not impose any financial burden on the States and would be so arranged that there would be the least possible inconvenience involved for these agencies. A request by Dr. McKusick for cooperation from the States that were represented brought affirmative replies from 10 of them.

APPENDIX B

Review of Development of the Model Reporting Area for Blindness Statistics

Hyman Goldstein, Ph. D.[1]

About 6 years ago the Biometrics Branch, NINDB, started actively to look into the possibility of securing comparable data on the incidence and prevalence of legal blindness among States maintaining blindness registers. After visiting every State in the country that at that time maintained a blindness register of any type, staff of the Branch concluded that there was great variation among the States visited in the type of data collected and the manner of collection, in the definition of blindness used and, consequently, in the eligibility of persons for inclusion on the register and for services available, in the updating procedures, if done at all, and in the uses to which register data were put.

After meeting with its planning group, the Biometrics Branch set up standards for admission to a proposed Model Reporting Area for Blindness Statistics (MRA) which were approved. The MRA was established in 1962 and has grown at a rate determined largely by the willingness and ability of a State to meet the standards and by the availability of funds and personnel to the Biometrics Branch to meet the obligations imposed on the Branch. Some of these obligations related to the letting of contracts to States to assist them in the initiation of new registers or improvement of existing ones; other obligations related to furnishing consultation on a continuing basis to potential and actual MRA members.

Shortly after the MRA was established, the Branch became aware of the basic need to determine how completely legally blind persons were reported to their respective State registers. This is a problem that, as far as is known, has never been tackled. There are, of course, a number of estimates based mainly on hunches and on a knowledge of the nature of blindness as a rather disabling condition. These estimates range from 80 to 95 percent. But there is no valid estimate based on survey. As a result, the Biometrics Branch requested funds over a period of years to conduct studies of completeness of reporting concurrently with attempts to groom States for admission to the MRA. Funds, however, were not made available to the Branch for such studies.

There are now 14 States in the MRA. An additional three States, Georgia, District of Columbia, and New York, are being groomed for membership. Five other States, Maryland, Texas, Michigan, Colorado, and North Dakota, are interested in securing assistance to meet MRA standards.

The MRA has attracted considerable interest both here and abroad as the first attempt anywhere to apply a set of standards in the collection of data on blindness so that such data may be compared or pooled.

In August 1965 a copy of a report from Senator Lister Hill's Committee on Appropriations with respect to appropriations for fiscal year 1966 was made available to the Branch. This particular report dealt with the NINDB—recommended appropriations and included the following statement: "There is a serious lack of knowledge regarding the prevalence and distribution of eye diseases, especially the associated disabilities of the blind which contribute so much to their problems of daily living. The Committee regards the Institute's Model Reportlng Area for Blindness as an important step toward obtaining accurate information and believes that this program should be extended to include a wider and more representative

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national sample. In addition, the Institute should undertake epidemiological studies of glaucoma, myopia, and vascular diseases of the eye in an effort to discover the causative factors in these common eye defects. Of the additional funds provided, $500,000 should be allocated to the Institute's direct operation for these investigations, including the development of whatever new diagnostic instruments may be required." These moneys were included in the Institute's appropriations effective July 1, 1965.

After some delay, the Branch was informed by the NINDB administration that a review panel, composed of an opthalmologist and three biostatisticians, would be set up to seek "an updated critical review of the activities of the Model Reporting Area and background information for an equitable allocation of positions and funds." The charge to this panel was as follows: "For purposes of future planning, this Institute would find it most valuable to have a clearly objective appraisal of this undertaking, that is the Model Reporting Area for Blindness Statistics with respect to (*a*) its overall mission and the attendant implications for research or service in the interest of improving public health or both; (*b*) its methodology with appropriate consideration to the adequacy of control on quality of all assembled data; and (*c*) the need for, and recommended direction of, any such change as may be necessary to achieve realistically defined objectives."

The panel met with senior staff members of the Biometrics Branch for several hours on November 3, 1965, in general discussion of objectives, procedures, and problems. There was considerable discussion about MRA objectives, plans to reach these objectives, the MRA quality control program, and other aspects of the program. Materials, publications, and copies of correspondence were furnished to the panel before and after the meeting. The panel as a whole or individual members of the panel met or communicated with several directors of State blindness agencies in the MRA program, with representatives of the National Society for the Prevention of Blindness, American Foundation for the Blind, National Center for Health Statistics, and the Neurological and Sensory Disease Service Branch, representatives of the Social Security Administration, Welfare Administration, Vocational Rehabilitation Administration, and of various other Biometrics Branches at NIH.

The report of the panel was released early in December 1965 and includes material dealing with the need for, and origin of, the MRA, and its standards. The report also dealt with development of the Standard Classification of Causes of Severe Vision Impairment and Blindness, the endorsements from the various agencies such as the American Academy of Ophthalmology and Otolaryngology, the AMA Section on Ophthalmology, the American Optometric Association, and the Council of State Directors of Vocational Rehabilitation. It mentions the recommendation of Dr. L. D. Duane in his book "Ophthalmic Research: U.S.A.," to the effect that the goal of MRA is highly commendable and should be pushed to conclusion without delay. It also refers to the fact that there have been annual meetings of the MRA at which papers were presented, summaries of achievement discussed, etc. It includes a map showing the States now in the MRA or being groomed for admission. There is some discussion of the fact that although about 19 percent of the population is now covered by MRA and another 12 percent, including New York and other States, expect to be covered within a year, there is apparently a serious disproportion geographically. Most of the MRA States are on the East Coast. Certain of the census divisions of the country are very poorly represented or not represented at all. There is a discussion of the cost of blindness to the Nation, and an estimate is made that such cost overall certainly comes close to a billion dollars annually. This figure may not include other things such as loss of income or tax revenue that may result from blindness.

The report indicates that ascertaining the cost of blindness is a research problem here befitting the detailed attention of a group such as the Biometrics Branch, NINDB. There is mention of the usefulness of blindness statistics and the various kinds of users of blindness statistics. There is some discussion about absolute and relative blindness and it touches on the matter of functional blindness, but it is

indicated that it is not reasonable to expect that the Model Reporting Area should at this stage venture far into this complex domain of description. It points out that the opportunities for imaginative leadership from MRA in both stimulating research by others and accomplishing statistical research itself are broad indeed, and that these needs surely constitute a challenge worthy of most careful administrative consideration.

The report states: "It is an evident fact that any program dealing with the control of a disease requires a basis of knowledge of the occurrence of this disease in the population as complete as possible both as to extent and as to type. To this end it is necessary to procure data which will define (*a*) the extent of the problem as measured by prevalence of the disease condition together with all available evidence of the incidence and (*b*) the nature of the problem, including data as to type of disease, individual and population characteristics, and all the additional information needed to assess the impact of the disease on the total community. It should be a major function of a Model Reporting Area to study methods for determining the completeness of rosters for the validation of reported conditions and for the following changes in conditions: i.e., additions to and deletions from the register. The development of a system of case finding is therefore an essential component in the prime objectives of a Model Reporting Area. In order to obtain reliable information on the nature of the impairment, its extent, causation, and prognosis, together with information that could be used for genetic studies, it is necessary that the patient be studied by a fully qualified specialist in the field of vision. It is clear that such information can never be obtained on a broad basis so as to include all persons on a complete register. It is therefore necessary to devise, with adequate care, a system of sampling studies which will yield data referable to the whole field. The function of a Model Reporting Area can then be considered as divided into two parts: (1) the development of the mechanism of recording, as completely as possible, the existence of cases of blindness and the occurrence of new cases so as to delimit the extent of the problem; (2) to serve as a base for devising sampling studies which will give information on an intensive basis regarding the nature of visual impairment."

The recommendations of the panel report pertaining to MRA are as follows:

(1) The MRA should be continued. The data being collected are of definite value in carrying forward an important mission of NINDB. Reliable data of the nature that MRA will develop are not otherwise currently available, nor does any other service organization appear likely to provide such data. Every organization or person consulted by the panel commended MRA for its accomplishments in the direction of securing uniformity of definition and cooperative reporting of blindness by the member States;

(2) As MRA progresses in its data collection it is anticipated improvement in the collection system will be developed. Certainly, such improvement should be incorporated into MRA as they appear. On the other hand, it is possible that completely different methods of obtaining such data may be developed. In such a case, if new methods are more efficient and productive than those of MRA, then it is to be anticipated that MRA will be replaced by another system of data collection;

(3) In the event that MRA develops into an operation of wide coverage of prospective permanence, it is suggested that the operation be left more completely in the hands of the States in a manner parallel to that of the present vital statistics systems as conducted by the National Center for Health Statistics. The function of MRA within NINDB would then be as a collection and integration point for the data from the several State registers, and a coordinating center for the separate operations;

(4) It is most important, for the time being, that validation of the methods being used by MRA, and any others being developed, be expedited. It is emphasized that such validation should not only precede any further expansion, but also be built into any future expansion of MRA. Statistical completeness and accuracy of the component registers is an obvious requirement for interregional comparisons to be made or national estimates to be formed from assembly of all data. The consistency of medical opinion needs to be documented on a continuing basis. Whatever be the method of validation devised, the tests themselves should be performed independently and not by staff of the Biometrics Branch, NINDB. The validation work should be developed within the existing geographic limits, and possibly within very small areas. It is also recommended that the use of ongoing Human Population Laboratories not be overlooked in this connection;

(5) While it is recognized that foreign projects may have a great deal of merit, the panel did not feel

its charge warranted a consideration in depth of these projects. It did conclude, however, that although these projects may be of outstanding potential, they should not be allowed to divert the Branch Chief and his staff at this time from concentrating on the problems of blindness within the MRA; and

(6) The panel did not have time nor opportunity to explore the Branch Chief's stated position that the Biometrics Branch is understaffed. However, it is urgent to recognize that the supervision of cause-of-blindness codes by only one person, as at present, is a hazardous administrative situation for a crucial part of the total program.

The Branch Chief was asked to prepare a plan which he did with the help of his staff, as to what the Branch intended to do in light of the report. A draft of the plan, as well as the panel report and its recommendations, were reviewed with the advisory group of the MRA in January 1966. As of the time of that meeting, neither funds nor positions resulting from the congressional recommendation (adopted and incorporated into the appropriations for the NINDB for fiscal year 1966, starting July 1, 1965) had been received by the Biometrics Branch.

The plan that was submitted first undertook to reply to the six recommendations. With respect to the first three recommendations, no action was requested on the part of the Biometrics Branch which was in general accord with them. Indeed, the MRA has been developing from the point of view envisioned by them.

Comment on the fourth recommendation may be withheld for the moment. The panel stated, in connection with the fifth recommendation, that it did not feel its charge warranted a consideration in depth of any foreign project which is not, and cannot be, a part of the MRA. Such projects are not considered an integral part of the MRA but merely ancillary interests of NINDB and NIH. The one foreign project undertaken, namely in Egypt, has taken very little staff time, has already produced recommendations in methodology for use in this country in visual screening survey projects. The screening methods developed and used in the Egyptian project may be of great help in proposed completeness of reporting projects for use in this country. The sixth and last recommendation indicated that even without study of the Biometrics Branch staffing problems as they relate to the MRA, it was obvious that there was a critical shortage of medical cause coding personnel. The shortage in statistical staffing was not even explored by the panel.

Coming back to the fourth recommendation, the panel had suggested that: (1) Validation studies and methods be undertaken and developed and that these methods and studies should not only precede any future expansion of MRA but also be incorporated into any future expansion of MRA. In other words, expansion of MRA at this point should be stopped until studies were done to determine completeness of reporting and validation of the data; (2) the Biometrics Branch not be involved in making these studies (this was later clarified by the chairman of the panel to include the Branch in planning such studies); (3) that such studies be done within the States and in small geographic areas; and (4) that the National Health Survey and ongoing Human Population Laboratories be contacted to explore possible assistance.

With respect to the fourth recommendation, it was the plan of the Biometrics Branch to carry forth concurrently (1) Completeness of reporting and validation studies, and (2) expansion of the MRA to include at least key States which are urgently needed for research purposes and for reliable national estimates of blindness. The basis and reason for this approach for the further development of MRA are quoted from the proposed plan. "The Biometrics Branch is in complete agreement with the Panel's recommendation for completeness of reporting studies. The Branch has on a number of occasions over the past few years requested modest funds in which to initiate studies such as these but such funds were not made available. Therefore, the branch is gratified with the recommendation the panel made on this aspect of the program. There is full agreement with the panel that these studies should have a high priority. Such belief is held despite the opinions of several directors of blindness register agencies contacted by the panel that their registers were from 80- to 95-percent complete, and despite the fact that the nature of the blindness impairment is such that even most of the relatively few well-to-do blind persons sooner or later are expected to seek

such services as talking books from official agencies and thus become known to the register. The Biometrics Branch plans to determine which organizations, if any, can and will assist it in validation studies. For reasons of feasibility it will attempt to use organizations that already have existing overheads, including staff and survey facilities. An attempt will be made to build validation procedures if possible, into already existing operations. In this connection it is planned to contact survey agencies that appear to be capable of conducting completeness of reporting surveys and to discuss with their appropriate staffs the possibility of undertaking approaches by which the objectives of the surveys may be reached feasibly within the scope and nature of the MRA program. Where an agency can be of assistance, details would have to be worked out with reference to the area or areas for such studies and with respect to the nature of the screening check such as questionnaires, visual acuity screening, etc. It is obvious that for maximum usefulness completeness of reporting projects would eventually have to be conducted in every MRA State, and that some provision would have to be made for periodically repeating such projects. This is so because the findings in any one community cannot per se be assumed to be true for other communities in a given State and the definings of any one State cannot necessarily be expected to hold for other States. Since one cannot presume that completeness of reporting is static such evaluations must be repeated periodically."

Contacts were made with the National Health Survey and with the Bureau of the Census. The Chief and Assistant Chief of the Biometrics Branch met with an official of the National Center for Health Statistics on January 6, 1966, and reviewed with him the background of MRA, pertinent aspects of the panel's report and its related recommendations. He gave careful consideration to the size of samples required for the proposed survey as they relate to the desired objectives and concluded that, because of the relatively low prevalence of blindness, superimposing the completeness of reporting survey on the existing National Health Survey procedures would not yield sufficient cases of blindness to meet the objectives of the completeness of reporting check. He suggested the need for "tailormade" ad hoc surveys which the National Health Survey would not be able to conduct. In his opinion such ad hoc surveys would be both time-consuming and very expensive. He referred the Biometrics Branch to the Bureau of the Census in order to determine whether or not that agency could be of assistance.

The Chief and Assistant Chief of the Biometrics Branch met with several representatives of the Census Bureau on January 12, 1966. Again the background of the MRA and the pertinent aspects of the panel's report were reviewed. After detailed discussion there was a general consensus that any completeness of reporting surveys required to meet the necessary objectives would be very expensive and time-consuming. It was also suggested special ad hoc surveys would be required rather than the incorporation of such surveys into existing normal Census Bureau operations. They indicated at that time that further thought including considerations of cost would be given by the Census Bureau's staff to this matter and they would report to us. At a later date we were informed that a survey of a single small community, including ophthalmological information of those picked up as blind, might involve a cost of $250,000. It is planned, however, to consult with representatives of other agencies such as the University of Michigan's Survey Research Center. However, it is doubtful that the Survey Research Center could meaningfully incorporate the validation surveys in its ongoing national surveys since that Center utilizes even smaller samples than the National Health Survey. It is planned to contact the Internal Revenue Service in order to determine whether data are available from that agency with reference to Federal income tax exemptions of blind taxpayers and their spouses in MRA States that will permit some evaluation of the extent of underreporting. A contact with that agency several years ago, for such purposes, had proved fruitless because no data on blind dependents but only on blind taxpayers and their spouses requesting exemptions for blindness are available to the Internal Revenue Service. Furthermore, many blind persons do not have enough income to require them to file

income tax returns. According to present plans, the potential of other agency systems such as that of the Social Security Administration would also be investigated in this connection.

In its fourth recommendation the panel referred to the potential use of Human Population Laboratories for purposes of validation studies. In this regard, with the exception of a so-called laboratory covering a very restricted geographic and socioeconomic area in upper Broadway in Manhattan in New York City, there are no Human Population Laboratories in States that are now in the MRA or that possibly would be admitted within a year. Therefore, the use of such facilities for validation purposes within the present MRA was limited.

Mention should be made that the Branch's inquiries at the National Health Survey and the Census Bureau indicated that even if it were possible to include MRA surveys into ongoing surveys of these agencies, this could be contingent on existing budget and schedule restrictions of these other agencies. Special ad hoc surveys were possible and generally could be initiated with less delay. But it would nevertheless take as long as 1½ years to plan, conduct, and analyze the data even of a single survey limited in scope such as that of a single small community within one State. It is apparent that any completeness and validation studies must be planned carefully and that they require a great deal of time and money to conduct.

As soon as possible and where feasible, attempts will be made to set up studies to visually screen samples of residents of nursing and rest homes in communities covered by MRA registers, in order to determine to what extent such residents have been under- or- over-reported to registers. If feasible and having potential, it is also planned to undertake studies where it may be possible to check hospitals, clinic and physician records for cause-of-blindness information against register data. If such studies are possible to do, they may help to validate information on cause of blindness insofar as indicating whether the register data accurately reflect what was on the hospital, clinic, or physician records. Such a study is being planned with the Ophthalmology Department, Mt. Sinai Hospital, New York City, whereby it may be possible to check against the New York State blindness register the medical and other data from the records of patients adjudged to be legally blind in that hospital and other institutions in New York City.

It is planned meanwhile to continue to improve the quality control program relating to cause of blindness that is now in operation in the MRA program. The quality control program is probably the only one of its kind in any large-scale morbidity reporting system in this country or even throughout the world. This aspect of the MRA which has great potential for research activity on etiology of blinding conditions will be given increasing emphasis. In this regard it may be noted that the Biometrics Branch experience has promoted and will continue to promote the adoption throughout the MRA of a standard eye examination report form, particularly with regard to reporting cause-of-blindness information.

The second part of the proposed Biometrics Branch plan deals with the relationship of completeness of reporting studies to further expansion of MRA. The panel recommended that the MRA not undergo any further expansion until all the validation and completeness of reporting studies have been completed. It is evident that securing information on completeness of reporting or on validation of cause of blindness depends on a number of factors that affect the possibility of getting such data and the duration of time it would take to do so: (1) Determining the nature of studies which it may be feasible to do; (2) finding an agency that is staffed and willing to undertake the studies needed; (3) determining how soon such studies can be scheduled by such agencies; and (4) duration of time to plan and conduct studies and to analyze the data. These are, of course, also dependent on securing the necessary cooperation of blindness register agencies, hospitals, clinics, physicians, and the population to be surveyed. Further, the extent to which such studies can be done must be largely contingent on budget limitations since they generally are very expensive to do.

It is evident that validation takes time; it is not an easy job. It may necessitate a number

of approaches and a number of pilot studies. Much planning and much careful thought are essential. Validation is a continuing process and is never really ended. Further, it must be kept in mind that, although at present the total MRA population distributions by age group, sex, and race (white and nonwhite) are quite close to those of the United States as a whole, geographically they are not representative of the total United States. The MRA, including the three States now working toward membership, represents a disproportionately heavy population concentration on the East Coast. As a matter of fact, in two of the nine census geographic divisions there are no MRA States. States in other geographic divisions are very meagerly represented in MRA. To quote from the panel report, "This imbalance is a natural consequence of the voluntary acceptance of MRA requirements of the States concerned and the multiple self-selection procedures operating within them." In other words, a State gets into MRA on its own volition; there is no compulsion. The State can stay or leave. This would automatically mean that it is not a random sample of States.

The MRA now covers about 19 percent of the total U.S. population and possibly within a year, with the addition of three States, New York, Georgia, District of Columbia, it will cover about 31 percent. A determined effort will have to be made to secure for MRA membership certain key States in order to establish greater geographic representation. These key States include those with large populations, those located in different geographic areas and/or those with population concentrations of certain ethnic groups. Such States would not only materially improve the geographic distribution of the MRA, but would also provide greater coverage of the U.S. population.

As noted above, the present composition of the MRA is largely deficient from the point of view of geographic distribution, particularly in certain areas which are relatively densely populated. For example, there is no MRA representation in the highly industrialized and heavily populated East North Central division of the country called the Midwest. This division is composed of Ohio, Indiana, Illinois, Michigan, and Wisconsin. Not a single one of those States in the Midwest is in the MRA.

The addition to MRA of key States would provide a firmer basis for projection of data of the MRA to a national level. The addition of such States as Texas, Michigan, and Ohio, among others which have expressed an interest, would add greatly to the eventual potential of the program. It is essential that the Biometrics Branch continue its efforts to include in MRA as many of the key States as possible that are willing and able to become members. Interest in the program has been shown by almost all of the key States. However, because of various local considerations or activities, such as reorganization going on within the State program, legislative actions, and preliminary efforts by the State toward membership, their membership to date has not yet been secured.

Efforts must be made to obtain, insofar as possible, an adequate coverage of the population with respect to known or suspected characteristics influencing the incidence or prevalence of blindness. These include, in addition to geographic location, such characteristics of the population as age, race, sex, ethnic groups, etc. Adequate coverage of this type is essential for certain kinds of research studies. It is known, for instance, that some diseases such as diabetes are causally related to blinding conditions and that certain ethnic groups may be more prone than others to such diseases. Consequently, some consideration must be given to ethnic characteristics in MRA coverage. One of the most feasible ways to achieve adequate coverage of ethnic groups is through adequate geographic coverage.

The importance of an adequate coverage of MRA was clearly indicated by the panel itself: "Geographic distribution of a particular type of blindness could provide clues to the etiology of blinding diseases of unknown origin such as uveitis. Some forms of cataracts have identifiable etiologies, others do not. Dependable information on a broad scale is needed on macular degeneration as an all-too-commonly responsible factor of visual loss in advancing age. We know little about this obscure and incapacitating ocular disease in relation to its distribution among the sexes, the geographic

areas involved and the influence of the socioeconomic factors." In this light, it is interesting to note the observance by the panel that a function of MRA is "to serve as a base for devising sampling studies which will give information on an intensive basis regarding the nature of visual impairment." The Biometrics Branch has been working toward this goal.

The aim to establish and maintain the registers in a uniform manner with complete and reliable information is an ongoing activity and indeed a membership requirement of MRA. It is planned to place greater emphasis on this research aspect of the MRA in the future. An attempt at projection of statistics in the MRA for purposes of national statistics must take into account, insofar as possible, factors which are known or suspected of having material influence on incidence and prevalence of blindness such as age, race, ethnic groups, and environment, including health, occupation, education, etc. Consequently, it will be best perhaps to think of the extension of MRA in terms of the extent to which such influencing factors are adequately covered within the MRA. Projection of data from MRA would be made by applying appropriate adjustments and weights to these factors, taking into account their distribution in the MRA as compared with the United States as a whole. In any consideration of further development and expansion of the MRA, one must give serious consideration to the matter of timing with respect to a given State's readiness to enter the MRA program. If key States are lost to MRA, research potential and rapport are lost. This may seriously reduce the potential of the MRA for producing reliable national estimates on blindness. Any appreciable delay in MRA expansion would result in corresponding delay in achieving such estimates. With respect to the matter of timing, it should be noted that, prior to the panel's review, the Biometrics Branch had encouraged certain States to improve their registers toward eventual MRA membership.

Of great importance is the fact that the Biometrics Branch will not consider assisting States interested in MRA membership which do not obtain in advance the cooperation and endorsement of agencies and professional people serving the blind within the State, such as various State departments, voluntary agencies, private agencies, ophthalmological and optometric societies, etc. All these factors are important considerations in responding to a request from a State for assistance in meeting the standards for admission to MRA. Any appreciable delay by Biometrics Branch to satisfy such requests may result in permanent loss of the State to the MRA program, particularly, since interest and enthusiasm for the program by all groups involved, within a State, may wane. It is the Branch's experience that timing is of the essence in this voluntary program. In view of the fact that validation studies take considerable time to accomplish, it would be in the best interest of the Nation to groom those States for MRA that are ready for such action. This may or may not involve the expenditure of Federal funds; however, it would greatly reduce the likelihood of subsequent necessity to undo a noncomparable approach to MRA procedures by a State that had been denied help from the Biometrics Branch. Where a State is interested in the MRA program and requests assistance, such help should be given as rapidly and economically as possible. It is in line with congressional intent that, "This program should be extended to include a wider and more representative national sample." Similarly, it is in accord with the recommendation made by Dr. Duane in his book to which reference has previously been made, "The goal of this study is highly commendable and should be pushed to conclusion without delay."

With respect to cost aspects, the MRA is certainly one of the least expensive methods, if not the least expensive of obtaining national blindness statistics based principally on ophthalmological examinations, since it utilizes already existing data collection mechanisms on a uniform basis. Such limited financial help, which is provided by NIH to these States, is of short duration and is directed only toward the improvement or establishment of blindness registers. All costs for subsequent maintenance of registers in MRA States are borne by the States themselves.

In view of the total goals of the program and the time it takes to achieve these goals, such as validation, etc., one must weigh the relative

priorities. While on occasion, validation might take precedence over expansion, it cannot be seen, at this time, why one precludes the possibility of the other, particularly since validation, to be meaningful, must be a continuing process. These two aspects are not in conflict. As a matter of fact, the panel indicated in its report, that the Biometrics Branch should not be involved in actually conducting the completeness of reporting of validation studies. The Branch, however, would have to be involved principally in the planning stage of such studies. It is highly advantageous to undertake both aspects, validation and expansion, concurrently, since both largely involve an interplay of time and funds. In this regard, it would be well to note that the representatives of the National Health Survey and of the Census Bureau, with whom the Biometrics Branch Chief and Assistant Chief met, have expressed agreement with this point of view, indicating that, in their opinion, both validation and expansion could and should, at the present time, go on concurrently. The Biometrics Branch strongly urged NINDB that it be permitted to pursue its plan for further development of the MRA, namely, to carry forth concurrently (*a*) completeness of reporting validation studies and (*b*) expansion of MRA to include at least key States which are urgently needed for research purposes and for reliable national estimates of blindness.

As indicated above, the advisory group to the MRA met in January 1966. After the presentation of the Biometrics Branch's prepared plan to the advisory group, there was considerable discussion. It was stressed that expansion should be based on some selective factors in addition to geographic location. Such factors would among other things, relate to the prevalence of blinding conditions in specific ethnic groups in a State population. A State with excellent facilities for conducting sample studies should get priority in considering where to undertake such studies. It was pointed out that, although blindness has a low prevalence rate in the population, it is among the top three most prevalent crippling diseases insofar as limiting the activities of an individual is concerned. There was unanimous agreement by the advisory group that expansion and validation be undertaken concurrently. It must be emphasized that the Biometrics Branch is of the belief that the review panel has conducted an excellent review of the MRA program in the short time allotted to the panel. There was just one honest difference of opinion which has been mentioned.

The following recommendations of the advisory group relate to the review panel report and to the prepared plan of the Biometrics Branch:

> The Model Reporting Area for Blindness Statistics Advisory Group has reviewed the recommendations of the review panel and the evaluation of these recommendations by the Biometrics Branch. It is the judgment of the Model Reporting Area for Blindness Statistics advisory group that the addition of a number of selected States designed to give a broader geographic representation would enhance the effectiveness of the MRABS reporting system and is an element in better validation. It further recommends that concurrently systematic efforts be made to develop methods for validating existing procedures. Because of the impact resulting from the expanded interest of the 89th Congress and of State legislative bodies in services to blind and other individuals with servere visual limitations, the MRABS advisory group recommends that the staff of the Biometrics Branch be expanded in order to meet these obligations and that funds be made available for this purpose. This program expansion is in keeping with the congressional intent as expressed by the Senate Committee on Appropriations in its Conference Report No. 537 attached to HR 7765, the HEW Appropriations Act for 1966.

Copies of the proposed plan of the Biometrics Branch, and the recommendation of the advisory group were sent forward to the NINDB administration shortly after the meeting of the advisory group. However, in March 1966 the Biometrics Branch was notified that in adherence, as completely as possible, to the review panel's recommendations the MRA would not be permitted to expand until the validation surveys were completed. In view of the fact that negotiations and consultations preparatory to setting up a contract with Maryland had been under way for about a year, the Branch would be permitted to proceed further with that contract. Some of the money appropriated by Congress for the MRA would be available to finance the conduct of validation studies.

Efforts are under way to set up two studies in line with the panel report. It is not expected

that contracts for these will be negotiated before the beginning of fiscal year 1967. These are: (1) a study of the validation of medical and other data available on blind persons in the records of a number of hospitals, homes for the aged, etc., in New York City for comparison with the New York State Blindness Register. The Ophthalmology Department of Mt. Sinai Hospital is assisting the Branch in this study. The New York State Commission for the Blind has indicated its cooperation; (2) a feasibility study prior to a completeness of reporting study in Vermont. This is a pilot study to determine what the problems are in trying to determine completeness of reporting. If the pilot study shows such studies to be feasible, a larger, statewide survey will be set up to get data on cases of blindness seen by all reporting sources in Vermont since 1960. This study should furnish the Biometrics Branch some idea of the problems in such studies and how to meet them in studies set up for other States or communities. The Vermont Division for the Blind is assisting the Branch in this study.

It is hoped that the Biometrics Branch will be given permission, once these studies have been started, to go ahead and assist other States requesting assistance to meet MRA standards.

It is expected that in States seeking assistance, a measure of completeness of reporting will be undertaken prior to admission. Also, as time and personnel permit, the same will be undertaken in States that are now members. In all cases the cooperation of the blindness registry agencies will be asked. Further, there will be no imposition on funds or personnel of these agencies in connection with these surveys.

APPENDIX C

The Standard Classification of Causes of Severe Vision Impairment and Blindness

Ralph G. Hurlin, Ph. D.[1]

The National Society for the Prevention of Blindness (NSPB) classification was adopted by the Model Reporting Area for Blindness Statistics (MRA) when it initiated this enterprise in which you are engaged, one purpose of which, I am sure you all agree, is to produce really sound statistics of the causes of blindness.

There are several things that I would like to say about the classification, partly because this will be the last year that I serve on the NSPB committee, and it may be my last chance to call your attention to some points that I think greatly need to be emphasized at this stage in the development of the MRA.

What I have to say concerns the use of the NSPB classification and its possible misuse. By "classification" we here mean the frame of categories in terms of which statistics are expressed. There is liability in the use of this classification, or any classification that is dignified by the adjective "standard." The use of a "standard" classification does not by itself assure that the statistics produced through its use will be sound.

I think it is extremely important that the adequacy, and also the comparability, of the registers of the MRA member States be competently tested, and the inadequate registers be brought up to a reasonable standard of adequacy, if the very large present expenditure of effort and funds for the production of statistics of blindness presumed to be comparable is to be continued. But equal emphasis should be placed on the need for other tests of validity of the data that you are producing.

As you well know, the NSPB classification is a dual classification, one by site and type of affection, the other by etiology. It is, in fact, two classifications of the causes of blindness. The principle of twofold classification was first applied in the preparation of cause-of-blindness statistics by the committee which originally devised the NSPB classification. I think we can take some satisfaction from the fact that it has become widely accepted. The dual elements of the classification, as you know, are: first, the factor which immediately causes blindness, that is, the condition of the visual organ which reduces or prevents vision; and, second, the factor which started the process that resulted in the affection immediately causing blindness. Thus, statistics of the diseases (abnormal conditions) that are the immediate causes of severe vision impairment are derived from the site-and-type-of-affection part of the classification, statistics of the underlying cause from the etiology part.

The two parts of the classification are related. There isn't much point, really, in using one without the other, or in using them independently. The categories that are important are those that result from the combination of the two parts of the classification. If you wish to present data that can be evaluated by the user, you need to do what the committee that produced the classification earlier recommended, that is, cross-classify the data of the two parts. It is of interest to note that Dr. MacDonald in his compilation of statistics of causes of blindness in Canada, obtained from the register for all of Canada,[2] of which you all know, has presented the full cross-classification of the data. The figures in some of the cross-classification categories are small, but they are not

[1] Chairman, Subcommittee on Classification, Committee on Operational Research, National Society for the Prevention of Blindness.

[2] Causes of Blindness in Canada, by A. E. MacDonald, M.D. Canadian Medical Association Journal, February 6, 1965.

therefore insignificant. The detail of the cross-classification provides one means of forming an opinion as to whether or not the statistics are good.

I wish to say something about revision of the classification. Our committee indeed is subject to criticism for its long delay in getting to the point of publishing the classification as it is now being used. Some changes in the categories have been made while it has been in use by the Model Reporting Area. Such changes are annoying, it is true. Those that have been made since adoption of the classification by MRA have not been drastic, and have been intended to increase the usefulness and comparability of the statistics being produced. The classification is now to be put in print. It will need revisions in the future, however, and should be revised as need for revision is found.

MRA's adoption of the classification and your use of it have been the means of its very important improvement in another respect. Before MRA accepted the classification, we had the two lists of categories, not very different from the two lists as they now are. They were indefinite categories, identified only by labels. Those using the classification had to make their own decisions to a very great extent as to what should and what should not go into the respective categories. As a result of a large amount of work that has been done by the committee, jointly with the MRA staff, and contributed to very importantly by the careful coding that has been done in the States, we have produced an extensive index of diagnostic terms that in effect defines the categories of the classification.

With ample reason Mr. McCollam reminded us yesterday of the inconvenience resulting from the delay in getting the index in something like final form. It is now in your hands in print, but it is not yet actually published. We regret the inconvenience, but believe that the time taken for production of the index has been well spent. It is fair to explain that the committee is voluntary and has worked without benefit of grant or appropriation. The work on the index has been influenced by the stream of problems that the coders have been sending in to Mrs. Moorhead, by her very skillful review and treatment of those problems, and by the opinions obtained on coding problems from Dr. Richard E. Hoover, as ophthalmological consultant to the Biometrics Branch.

The index is, in fact, part of the classification, since it defines the categories. We have talked of it as a tool to assist in classification, and you have testified that its use does greatly simplify the process of coding. Its more important purpose, however, is to promote uniformity in coding, which is essential for the production of comparable statistics.

The NSPB classification has been accepted in principle outside the United States. Dr. MacDonald has used the 1957 edition in his tabulation of cause data reported for the register maintained by the Canadian National Institute for the Blind. The principle of the classification is incorporated in the plan for blindness statistics of the British Ministry of Health. The classification was used by Dr. J. Schappert-Kimmijser in her recent study of the causes of blindness in the Netherlands, and with slight modification it was adopted in 1961 by the International Society for the Prevention of Blindness. There is, obviously, much to be gained from the use of essentially comparable classification plans, but the fact that needs to be recognized is that the adoption of a standard classification—that is, a standard list of categories in terms of which to express statistics—is far from enough to ensure comparability or soundness of the statistics obtained. We should be concerned not with the use of a standard classification only, but with the use of a total standard procedure for the production of cause-of-blindness and other blindness statistics.

The Model Reporting Area is in the process of instituting a standard procedure for production of cause-of-blindness statistics. But, if I can be permitted to be critical, I would like to say that I think its present procedure needs improvement in several important respects. I shall indicate them in enumerating what seem to me to be the six essential parts of a good standard procedure for the production of cause-of-blindness statistics.

The first essential requirement is that a standard definition of the indefinite term "blindness" be used in the collection of diagnostic data. MRA provides a perfectly definite definition of the term "blindness," but I am not

at all certain, and I am sure you are not at all certain, that it is actually being used effectively in the collection of the diagnostic data you are tabulating. I think that many of the physicians who are reporting cause data that you are using are, in fact, reporting for a more restricted concept of blindness than that specified in the MRA definition, and that to that extent your statistics are not what they seem to be.

The second requirement is that diagnostic data be accepted for tabulation only from physicians who are specialists in ophthalmology. MRA makes this requirement.

The third condition I propose is that the diagnostic data used should be collected through the means of, and should represent, only mature registers of blind persons. By a mature register I mean one that represents substantially the total blind (as the term is defined) population of the area concerned. The rates of blindness do not change greatly from year to year, so that in a mature register an approximate balance is to be expected between additions and removals. In each of the MRA member States blindness statistics are being obtained through the operation of a register of blind persons, but as yet no tests have been required of the adequacy of the registers, and statistics from States whose registers probably approach adequacy are being combined for the total Model Reporting Area with statistics of other States whose registers are shown by their statistics of additions and removals to be immature.

The fourth and fifth of my proposed six parts of a desirable standard procedure for producing blindness statistics need no explanation. The fourth is the use of a standard twofold plan of classification, or list of categories; and the fifth is the use of standard coding procedures. MRA makes both these requirements and, by means of its effective plan of current quality control, assures that they are substantially met.

My sixth proposed requirement is not made as yet by MRA. It concerns the collection of data from participating physicians. A very large amount of time and effort is now spent in promoting standardized coding of data which are not collected in a standardized manner, and much of which is not reported in a way in which it should be accepted for scientific use. The sixth requirement is that a standard report form be used in collecting diagnostic data. It is not enough to ask, as some of the report forms now in use in MRA member States do, only for some entry on the form in answer to the question, "Diagnosis?" The question must be asked in sufficient detail to show the physician what information concerning his diagnosis is needed for the statistical purpose.

Blindness statistics present a much more difficult problem than do death statistics. Death is a discrete condition, it occurs and doesn't change. Blindness, on the other hand, is a variable condition. For most persons who become blind the degree of handicap changes, and the affections causing the impairment of vision may also change. What is responsible for blindness when one becomes blind will not necessarily be the most important cause of later visual impairment. This means that there is a great deal of difference between the problems of collecting cause-of-blindness statistics and cause-of-death statistics. It also means that cause statistics for new cases of blindness (incidence) can be expected to be significantly different from cause statistics for blind populations consisting of both old and new cases, unless the diagnostic data are collected in such form as to permit production of statistics for both old and new cases that pertain to primary causes of blindness.

I believe that MRA should have required the use of a standard report form from the outset, and hope very much that it will do so for the coming year. It is probably not essential that the forms used in each State be standardized in every particular, but the case seems entirely clear that the forms should be standardized with respect to the parts that call for diagnostic data.

In conclusion, I would like to return for a moment to the registers. MRA has demonstrated the need for registers of blind persons for statistical purposes. It is of interest that other than statistical uses are being found for them. Their utility to other agencies can assist in their development, but sight should not be lost of the facts that the statistical purpose is the primary purpose of maintaining the regis-

ters, and that inadequate registers cannot yield adequate statistics.

It may be impossible to secure complete registration of blind persons, but not impossible to bring the registers to the stage of approximate balance. Until that stage is reached—until a register approaches completeness—it is not a satisfactory source for any one of the three bodies of statistics the Model Reporting Area has undertaken to supply, that is, statistics of the prevalence, the incidence, and the causes of blindness.

Our present statistics on each of these aspects of the problem of blindness are unsatisfactory. As yet, we do not have even a firm basis for estimating the total number of blind persons in the United States. Nor have we yet, except possibly for certain of the MRA States whose registers are best developed, any statistics that are useful for estimating incidence of blindness. I have indicated my belief that there is need for further standardization in the production of cause statistics. But I should not like to end these comments without indicating that I believe that what already has been accomplished through the Model Reporting Area for Blindness Statistics is of very great value and that it can produce the statistics that are needed.

DISCUSSION

Miss Cole asked how the terms "primary" and "secondary to" are defined. Dr. Hurlin replied that the term "primary" is used by the medical profession sometimes to mean the condition immediately initiating the blindness, and sometimes to mean the first condition in a series of events leading to blindness. The term "secondary to" was a little more difficult to define. A sequela is a condition which follows from another. The earlier condition, i.e., the primary condition, leads to the sequela. Miss Tomasulo raised the question as to whether MRA anticipated asking the States to recode the complete registers according to the newly revised classification now in use, and if so, when. Dr. Hurlin indicated that the emphasis should be placed not on recoding but on getting good reliable statistics on new cases. In his opinion, the time and cost of recoding was not worthwhile, especially when the data were not in many instances adequate for coding in the first place. He would like to urge MRA to put its emphasis on first bringing the registers to a "mature" condition and then put emphasis on good coding of data that are fit to code.

It was brought out that 10 or 11 of the States in MRA and those applying for membership are now using NSPB standardized eye report forms. The others are not using it or not using it as a standard form. Mr. D'Andrea wanted to know whether, in Dr. Hurlin's opinion, the information coming from the latter States is inadequate so far as the reporting procedure is concerned. Dr. Hurlin indicated that the difficulty with using a form which merely asks for "diagnosis" is that it requires the physician to guess what you want in answer to that question. As a result, some physicians, because they think it is adequate or because they are in a hurry, put down one word. It then becomes necessary for the State coder, with the help of the index and the staff at Biometrics Branch headquarters, to decide what that one word means in terms of primary condition and etiology. Thus, such meanings, based on one word, must be either accepted or else the condition and etiology must be coded as "not reported." There is usually a great hesitancy to code "not reported." This results in forcing data into specific categories, and data that are forced, even by good coding, result in guesswork.

Mr. Goldberg stated that in many States there are other agencies, in addition to the register agencies, that distribute eye report forms. An attempt had been made several years ago at the national level to get agreement as to terminology on the eye-report forms that were being proposed to the States for adoption through their various Federal blindness programs. Such agreement was obtained on terminology at the time. The Federal agencies have agreed in principle with the philosophy of the cause-of-blindness form proposed by the National Society for the Prevention of Blindness. However, the Federal agencies cannot tell the States what to do. Therefore, it is important for the State agencies to take the next step locally to persuade other agencies to adopt the forms they would like to see in use. A great deal can and must be done at the local

level, as well as the national level, to bring about the desired effects. Mr. Goldberg urged the State register agencies to look into the forms produced by their agencies, and then to look into the forms received by their agencies that are produced by other agencies in their States. He pointed out that a number of States periodically have to reprint their form because of shortages of supply or for other reasons. It would be wise to revise their form at the next such opportunity and come out with a form more in keeping with that proposed by the NSPB. In this way the form would provide a maximum of information in key areas relating to causes of blindness. Miss Anderson confirmed the need for more effort in this direction at the State level.

Mrs. Lawlor indicated that the matter of a standard report form is of real concern to physicians and is one of the reasons they resist completing forms. She stated that the NSPB standard eye report form has many reasons for its use. The various Federal and State agencies asking for information regarding blindness do not always have the same reason for asking that this form be used. There must be more agreement, at least among the MRA States, as to what information is wanted. She pointed out that "near vision" is requested on the NSPB form. The New York State experience has been such as to indicate that this item has little influence on the classification of causes of blindness. As a result it was removed from the State eye report form. Although educators want information on "near vision," that is not the reason that New York State uses the eye report form it does. In her opinion it would be impossible, because of the diversity of interests of those interested in blindness reporting, to get a real standard report form. She was of the belief that the most one could hope for was a form that could be developed by the Federal and State agencies working together to include items pertaining to their respective needs. However, such a form should not necessarily require the physician to fill in each of the different sections.

Mr. Gambaro commented that most of the agencies designed forms to serve the agencies' special needs. In his view, there should be room on a standard form so that the agency's peculiar or particular needs also can be served. As an example, he stated that the District of Columbia Department of Public Welfare will not accept a form that does not have incorporated a certification of blindness statement that the ophthalmologist must sign. He further stated that since all eye report forms come within the purview of the ophthalmologist, it may be necessary, before any changes are made in the eye report form, to get approval from the various ophthalmological groups. Perhaps after the ophthalmologists have endorsed a new form, it would be easier to persuade the various national and State agencies to accept it.

Dr. Goldstein urged the State representatives to solicit the endorsement of MRA and its objectives from State societies of ophthalmologists and optometrists in line with endorsements already secured from all the national medical, ophthalmological, and optometric groups. This would make it easier to get endorsement of a standard eye report form by the various agencies.

Miss Cole suggested that it might help if copies of the desired standard form were offered free to other agencies for their use. Agencies would be more apt to use the form under such circumstances.

Dr. Hurlin stated that the prestige of MRA was now great enough so that it could be used as a lever in getting some cooperation in this direction from other agencies. He though that MRA should indicate that it would not accept figures from any register where the agency is not using a standard eye report form. In his opinion, this would get agencies to agree to use of a standard form rather quickly. He was of the belief that specific information not in the standard form that is needed by the particular agency could be supplied by a supplementary form. However, it should be recognized that the data needed for the MRA register is the primary purpose of the standard form. The supplementary form could differ for different agencies. Both Miss Cole and Miss Anderson indicated that this now is being done in their States.

Mr. Friedensohn stated that the NSPB form has not yet been able to secure the approval of his advisory committee composed of 15

ophthalmologists in the State. Since these physicians interpret for the rest of the profession, it is doubtful whether it will be adopted by other ophthalmologists in New York State. It would appear to be a matter of need for more time and more education. Mr. Perry indicated that at a meeting of ophthalmologists in Utah several weeks ago, the form was discussed but it did not receive approval because it was thought to be too complicated and misleading. There was difficulty in understanding parts of it.

Mr. Stocker said that in Oregon the ophthalmologists say it is a statistical report form and not a medical one. In reply, Dr. Hurlin stated it is a report for getting better statistics on causes of blindness. If the physician is interested in the cause of better statistics, he has to file a statistical report. Invalid or spurious data cannot be accepted. It is not only important to find out what the present condition is but, more important, to determine what preceded the present condition if valid statistics on causation are to emerge. Mr. Goldberg mentioned that the death certificate is, in essence, also a statistical report that tries to get at the underlying cause of death.

Mrs. Hatfield made two comments: (1) A death certificate is a required form. It is used for statistical purposes and was developed with the help of physicians but not solely by physicians just as the NSPB form was developed for statistical purposes with the help of ophthalmologists. It is inconceivable that ophthalmologists alone should make the final decision as to what to include on the form. It is obvious that they would make the form as simple as possible and would include just what they want rather than what is needed; (2) The NSPB school eye report form which is a modification of the NSPB form under discussion has been widely accepted throughout the country in schools for the blind and in public schools. A study will be undertaken in the near future to determine how well the diagnostic section is being used. When the form was introduced there were mixed reactions. Some ophthalmologists accepted it and said it was a good form; others did not. There will be mixed reactions no matter what form is used.

Miss Ford stated that in view of the remarks made about the variety of eye reports that the MRA States are confronted with, she was introducing at this time a resolution for consideration by the Conference to the effect that the Federal agencies be requested to adopt one approved eye report form to be used throughout the United States by all agencies with blindness programs. This resolution was seconded and unanimously passed.

APPENDIX D

Proposal for a Continuing Analysis of Model Reporting Areas Experience

Irving D. Goldberg [1]

A study on the survivorship and causes of death among the blind, based on the Massachusetts register, was conducted by the Biometrics Branch, NINDB, with the cooperation of the Massachusetts Division of the Blind and embraced a 20-year followup period. Three papers have been published on the basis of that study.[1 2 3]

The success of that study led the Biometrics Branch to a consideration of the value of a longitudinal study into the subsequent status and survivorship patterns of persons registered as blind with the Model Reporting Area (MRA). (By longitudinal study I mean the followup of the same persons over a period of years.) The manner in which the registers are being maintained in the MRA States makes it feasible to conduct such a study on a continuing basis in a prospective manner without any material burden to the States themselves.

The term "prospective" would imply the followup of persons from the time they are reported until they die or are otherwise removed from the register or until a fixed number of years have passed. This procedure would be in contrast to the retrospective approach taken in the Massachusetts study where we attempted to determine what happened to persons reported as much as 20 years ago.

Objectives of the Study

The objectives of the proposed study are severalfold, as follows:

(1) To determine on a continuing basis the survivorship rates of severely visually handicapped persons in the Model Reporting Area States by such factors as age, sex, race, and cause of blindness; and to compare these findings with corresponding rates observed in the general population.

(2) To examine the records for causes of death by age, sex, race, and causes of blindness of those persons removed from the register because of death; and to compare these findings with corresponding distributions observed in the general population.

(3) To compare the survivorship patterns of the registered blind in each of the Model Reporting Area States with one another.

(4) To determine sight recovery rates.

(5) To determine patterns of readmission to the register by reason of prior removal.

(6) If possible, to determine the migration patterns of blind persons through followup of removals from the register. This objective may have to be considered carefully since it is possible that the study of migration may be faced with certain difficulties in the tracking down of migrants.

(7) If possible, to determine the effects on the survivorship pattern of various services rendered by blindness agencies. This objective will also have to be considered carefully in view of the fact that problems may arise in interpreting effects because of multiplicity or intermittent nature of services received by a person from time to time.

Sources of Information

Information for this study would be collected from a variety of sources, as follows: records of the blindness agencies in the Model Reporting Area States; death certificates from the vital statistics offices of the Model Reporting Area

[1] Assistant Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness.

States; and published data from the National Vital Statistics Division.

Study Plan

It may be desirable to initiate this proposal on a pilot basis by confining the activity in one State for perhaps 1 year, so as to determine what some of the problems might be and to provide a means for streamlining the methodology for application to the other MRA States. However, the basic study plan would be as follows:

Clearance must first be obtained from the vital statistics divisions in the various MRA States so that positive determination of the fact of death may be obtained and so that causes of death may be ascertained for such removals from the register.

In order to reduce to a minimum the number of blind persons lost to followup, each MRA State, with aid from the Biometrics Branch, would conduct a thorough search to locate those registrants who are removed from the register for reason of "unable to locate." The listings of the deaths maintained by the various State vital statistics divisions should be obtained and perused as part of this endeavor. Also, if possible, the records of neighboring MRA States would be examined to determine if registrants who could not be located have actually moved to another MRA State. (It would be hoped that eventually all of the States which have records on blind persons could be used for this purpose.) Details would have to be worked out with each State individually regarding the confidentiality aspect.

With regard to removals from the register for reason, "moved out of State," efforts should be made at the time of removal or as soon thereafter as possible to determine to which State such registrants have moved.

Since the registers of all but one of the MRA States are on punchcard systems, summary punchcards could be prepared from existing punchcards to include codes for cause of death, State to which moved, etc. This special deck of cards would then provide some of the basic information for this project without interfering with the regular register punchcards.

It may be desirable to use as a starting point for this study, all additions to the register beginning with the year the study is initiated, ignoring prior registrants for purposes of the study. An alternative approach might be to start the study with additions to a State's register since that State became a member of the MRA. Other starting points may be used. However, it should be noted that in some States it may not be simple to determine the actual date of addition to the register prior to MRA membership because of the way in which such information was kept in previous years. (Thus, "date of addition" prior to the MRA date might be fallacious or difficult to determine.) In any event, it is clear that the starting point might have to be considered very carefully since, among other reasons, it would be desirable to use a similar starting point for all States. I imagine that we would use the first alternative, that is, to start with the current additions to the register in the year in which the study is initiated, and also to include for followup all subsequent additions through the duration of the study.

Care must be taken to insure that, for each State and for each year, the register totals in a given State are accurate. Thus, the total number of persons on the register at the end of a given year plus the additions during the succeeding year, less the removals in that succeeding year, add up exactly to the latter year's end-of-year total on the register.

In general, the data which would be used in the study are already being collected and recorded on punchcards by the MRA States. The only limitations at the moment are (1) the fact that one MRA State does not yet have a mechanical punchcard system, and (2) that another State does not collect data on race (State law).

Analysis of Data

A life-table type of analysis by sex, race, and cause of blindness, similar to that used in the Massachusetts survivorship study, would be employed. Analysis can be conducted both on an individual State basis and for the MRA as a whole. Certain analyses might be started earlier for the total MRA than for individual States due to the fact that analyses for the total MRA would be based on larger numbers

representing the cumulative totals of blind persons from the various States combined.

I do not want to take the time now to go into a variety of detailed considerations which would have to be given to this proposal, with respect to specific types of analyses or specific procedures. These would be worked out at a later date.

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APPENDIX E

The Blindness Register Survey in Egypt[1]

Mohyi-Eldin Said, F.R.C.S. Ed.[2]
Ahmad Korra, M. Ch.
Khalil El-Kashlan, Dr. P.H.

It is a pleasure, an honor, and a privilege to express our thanks, as investigators of this pilot project which is the first of its kind in the world, to the National Institute of Neurological Diseases and Blindness.

We wish also to extend our gratitude to Dr. Hyman Goldstein, Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness, U.S. Public Health Service, for all that he did in helping us put into practice the project agreement through his mature and long experience in research work. Indeed, we owe much to his guidance and counseling which are unforgettable.

The University of Alexandria, in turn, as the second party to this agreement, takes pride in carrying out this project of which the main concern is a survey of the population represented, in an urban sector (Alexandria), by approximately 125,000 persons, and in a nearby rural sector (23 villages in Beheira Governorate), by a similar number of persons.

As to planning, execution, evaluation, personnel, equipments, and problems encountered, these details will be presented at this time for possible adaptation by other countries at a later date.

The objectives of the project are:

(1) To determine what, if any, modifications may be made in Model Reporting Area procedures to get comparable statistics in a less developed country.

(2) To determine the prevalence and causes of blindness in Egypt where the rate of blindness as determined by census is one of the highest in the world (0.35 percent or 355 persons per 100,000 population in the 1960 Egyptian census). This is about 1.7 times that estimated in the United States.

In the Egyptian census, blindness was recorded only if the respondent said he was blind. In the clinics the criterion for blindness is a visual acuity in the better eye of 1/60 or less, that is, if the person was only able to count fingers at a distance of 1 meter. In our project we are using the definition of blindness employed by the Model Reporting Area in the United States, namely "Visual acuity of 20/200 (6/60) or less in the better eye, with best correction, or visual acuity of more than 20/200 (6/60) if the widest diameter of the field of vision subtends an angle no greater than 20 degrees." From preliminary results, presented below, it has been determined that the prevalence rate of blindness with this definition is, in the urban areas, about 7 times that estimated for the United States, and, in the rural areas, about 23 times. Some idea of the magnitude of the problem in Egypt may be gained from such comparisons. Data are also available with respect to prevalence rates obtained by defining blindness as a visual acuity of 1/60 or less in the better eye with best correction. However, such data will be presented in a later paper.

It should be noted that there are three phases to this study:

Phase I entails examination of an approximately 4-percent random sample of house-

[1] This project is supported by agreement No. 522510 under the National Institutes of Health special foreign currency program.

[2] Dr. Said is Professor of Ophthalmology, Faculty of Medicine, University of Alexandria, Egypt, and principal investigator of the Blindness Register Survey. Dr. Korra is project control officer and Dr. El-Kashlan is chief statistician of the project. Both are on the Faculty of Medicine, University of Alexandria. The paper was presented by Dr. Said.

holds in the urban and rural areas in the study with approximately half in the urban and half in the rural areas. This resulted in examination of about 11,000 persons. This sample is subjected to a survey of the central visual acuity (and peripheral field where the visual acuity is better than 6/60 (equivalent to 20/200) in the better eye with best correction) to screen out those meeting the definition of blindness used by the Model Reporting Area. The purpose of this phase is to yield baseline prevalence rates of blindness by age, sex, urban and rural populations, and other variables.

Phase II entails examination of the whole population of the urban and rural areas selected for the study (approximately 250,000 people). The purpose of this phase is to build up the blindness register.

Phase III is a repeat of Phase I by reexamining those still alive and residing in the study areas of the sample of approximately 10,000 persons examined in Phase I. Comparison of the results of Phases I and III enables the calculation of incidence rates by age, sex, urban and rural areas, as well as other variables.

The site selected for the study is in the Governorates of Alexandria and Beheira. In the city of Alexandria two administrative districts were chosen (Attarine and Manshia) with an estimated population of about 127,810 at the beginning of the study in April 1965. In the rural area 23 villages were chosen with a population estimated at about 126,940. Very few individuals less than 5 years of age were examined. Examination of children at such an early age with the equipment used proved impractical and very time-consuming in the field. Of the 874 children under 5 years of age falling into the urban sample, it was possible to examine only 10 of them. Similarly, of the 441 children under 5 years of age in the rural sample, only 6 were examined for the reasons given above. It is planned to make a special study of this age group in Phase II by noting their appearance, behavior, and medical history. Those suspected of having poor vision will be subjected to more thorough examination.

Personnel of the project comprises the principal investigator, a project control officer, a statistician and his staff of 7 persons, 6 sight-screeners, 5 ophthalmologists, 18 social workers, nurses, clerks, and attendants, and administrative assistant, and 4 secretaries. This comes to a total of 44 personnel on the project.

As we do not have in Egypt a system of district nurses, we had to resort to junior physicians and assistant ophthalmologists for sight-screening. From the psychological viewpoint this encouraged the public to approve being examined. Physicians were trained how to handle the apparatus for a period of 2 weeks. Monthly reliability tests revealed comparability of their results. It should be noted that no false negatives were found during the 10-percent checkup carried out regularly by ophthalmologists in Phase I.

In Phase I the number required for examination was proportionately small, approximately 10,000 persons in 5 months'time. We provided six sight-screeners who could work one shift (3 hours per day for 6 days a week). This was determined by the number of sets of apparatus available. They were occupied in their regular jobs in the morning which limited their participation to one shift only. These six sight-screeners have examined the inhabitants of both the urban and rural sectors. In our view it was preferable that, since they had examined the urban population of the sample, they should also examine the rural population to insure uniformity of the data, rather than permitting the physicians in charge of the rural medical units to do so. In addition, it was not worthwhile from the practical viewpoint to train the doctors of the medical units for the examination of only 4 percent of their village population. Again, some of the villages screened have not yet been equipped with such medical units.

Nevertheless, in Phase II, the rural medical unit physicians were employed to screen the whole population of the rural sector, which amounted to approximately 125,000 persons, on the grounds that:

(1) The medical unit doctor has a certain prestige besides his own influence among the village population (as is the case with the family doctor in the United States). The people confide in him as he is always

among them; so that it is quite easy for him to convince them to come for sight-screening.

(2) Lack of harmony and cooperation might be the outcome in case sight-screening was carried out by a physician who was alien to the village.

(3) We had to save ourselves the trouble in transporting the sight-screener, his apparatus, and assistants, and to save as well the transport expenses and fares. Meanwhile, time that might be wasted in transportation might be more fully invested this way.

The sight-screener could examine about 30 to 40 cases in 3 hours' time (according to the experiments carried out during the inservice training). A case would take from 4 to 6 minutes, on the average, to be sight-screened (visual acuity in each eye separately in addition to perimetric examination) depending on the patient's intelligence and education. Refraction and visual acuity with glasses were tested, if the case necessitated. No cycloplegics or mydriatics were used prior to determination of best correction. However, a preliminary test in 10 individuals (20 eyes) as to the effect of using homatropine, as compared to not using any drugs, with the individual serving as his own control, showed that the average difference in acuity of vision after correction between use and nonuse of the drug was zero. In other words, there was no statistically significant difference observed. Most of the patients essentially in the rural area are not educated; most of them are illiterate, and sometimes it is quite a job to try to explain the tumbling E test and the apparatus, how to have his eyesight measured, and the necessity for obtaining the demographic and other data needed for the form. The form was completed by the social worker or the clerk and it took about 2 minutes. This process saved much of the screener's time.

Most of the sight-screeners employed are graduates of the Faculty of Medicine, University of Alexandria, and so did their best to make a success of the project.

Ophthalmologists were first selected from among the staff of the Ophthalmic Department, Faculty of Medicine. Although they were all highly qualified and all fellows of the Royal College of Surgeons and/or have the M. Ch. degree, the very first month of the study revealed that most of them did not have sufficient time to allot satisfactorily for investigation. Hence, we resorted for help to ophthalmologists who are not members of the staff and who could spare adequate time to work on the project and travel daily to centers of sight-screening at distant villages in order to supervise the sight-screeners' work, to examine the referred cases and to look for false negatives by rechecking 10 percent of the non-blind cases. Moreover blindness cases that were referred were to be comprehensively investigated and forms filled out on them. Periodic reliability tests of the ophthalmologists' diagnoses were made by independent examination of the same blind patients.

As for the social workers in Phase I we employed women graduates of the High Institute of Social Work (where the standard is equivalent to that of university graduates). It was the woman social worker's duty to enter the homes, introduce the purposes and goals of the project, and conduct interviews. Tete-a-tete conversations are most effective for this purpose. Moreover, according to our oriental traditions, male strangers not accompanied by women are not admitted into homes. Each team was composed of a sight-screener, a woman social worker, and an attendant to carry the apparatus. The social worker's contacts preceded the sight-screening. It took place either on the day before the sight-screening or in the morning of the same day. Screenings were in the afternoon from 4:00 to 7:00.

In Phase II in the rural sector we made use of the clerical staff of the medical units to perform the duties of the social workers as they knew the inhabitants and lived among them. The social worker's or the clerk's task was to fill in the social and personal data at the top of the forms in order to save the ophthalmologist's and the screener's time. As the forms were at first in English, it was easy for the social worker who knew enough English to fill them out. But since the clerks were not fluent in the use of English, we had to translate the required data to be completed by the clerk from English

into Arabic to make it easy for them to fill out the forms precisely.

The procedures in Phase I were as follows:

(A) The urban sector—

(1) A complete listing of addresses and families living in the two urban districts was obtained and a random sample of families was drawn by the statistical section.

(2) Families were distributed among the screening teams by the project control officer.

(3) In the morning, the social worker, assigned to each team, visited the families that would be examined in the afternoon, with a view to giving them an idea about the goals of the project and how much it would benefit them, as well as the society in which they lived.

(4) In the afternoon from 4:00 to 7:00 each of the screening teams went to the designated houses to perform the examination and to transfer cases screened out as blind to ophthalmologists for confirmation and for possible determination of the causes.

(5) An ophthalmologist was responsible for each team or sometimes two teams. Cases of blindness were transferred to his clinic (as this was the situation at the beginning of the program), or to the university hospital outpatient clinic (as proved more expedient as a result of later experience). The ophthalmologist was also responsible for checking 10 percent of the cases screened as non-blind. This was done in the afternoon, twice a week.

(6) On the next morning each team was to send a report of what has been accomplished, coupled with the screening forms, to the project control officer to check the progress of the work.

(7) The ophthalmologist, having reexamined those screened out as blind, had to send the forms, coupled with a daily report, to the project control officer who would check the data therein to make sure all the items were completed.

(8) Blindness forms were given to the principal investigator for rechecking.

(9) After the inhabitants of each subdistrict had been screened, then forms were sent to the statistical section.

(10) In the statistical section the names and addresses of individuals screened were recorded for future reference in Phase III. Also the data in the field survey sheets were coded, punched, and verified.

(11) Once the statistics section was through with these processes, the forms were returned to the project control office where they were filed.

(12) Meetings twice weekly were held among principal investigator, project control officer, and chief statistician to discuss the difficulties and progress of the work. Whenever it was needed, regularly and every 2 weeks, conferences with the whole staff were held.

(B) In the rural sector the procedures were as in the urban sector, except for the following modifications:

(1) To insure the cooperation of the population and the success of the study, contact was made with the mayor and other village officials.

(2) Sight-screening was mostly held in the health units in the villages. When these were not available, mosques, schools, or other convenient places were used. Examination in some of the distant villages was carried out even under a tree or in the open air. An ophthalmologist was always present with the teams in the field to examine the blind and to make the 10-percent checkup on the same day since it might be difficult to bring them back for reexamination at a later date.

The publicity for the project was carried out through personal contact with village authorities such as chairmen of village boards, mayors, and chiefs of villages. In addition other means of publicity such as newspapers and periodicals in Arabic and foreign languages, radio, television, and posters played an effective part in promoting the idea of the project.

The six sets of apparatus with which we were equipped limited the number of sight-screeners to six, with a set of apparatus for each team. The set included a Titmus optical

vision tester, a Schweigger hand perimeter, and equipment for refraction, retinoscopy, and lenses for correction. We could not manage to get screeners to work in the morning, so that the apparatus might be made use of in two shifts, in lieu of one afternoon shift. The reason why ocular physicians could not help us much in this connection was because they were occupied in their regular jobs until 2:00 p.m. Many medical projects in Egypt have been absorbing the efforts of physicians. As regards the apparatus and the difficulties with the apparatus, there were only six, as I said. Had we been equipped with 12, double the number, we would have employed 12 sight-screeners in the afternoon to examine greater numbers of persons and thus save time. Some difficulties were met with while handling the vision testing equipment; as follows:

(1) Optical vision testers: Inside the optical vision testers a Tumbling "E" slide is used. We are not well acquainted with the letter "E" in Egypt as we are with the Landholdt rings type charts which are commonly used. This undoubtedly led to spending a much longer time in testing depending on the patients' intelligence and education. To save time one of the assistants had to explain to people in groups the concept of the letter "E" before they were tested. Consequently, it is suggested that, in case this kind of project is carried out in other countries, the type of slide commonly used in the country in question be given priority consideration although it is understood that the need for securing comparable data from country to country may be paramount. It should be mentioned, however, that a correlation of 0.97 with 95-percent confidence limits of 0.99 and 0.95 was secured in a study of results secured by use of the Tumbling "E" slides and the Snellen Tumbling "E" chart on each eye in 15 individuals.

(2) Batteries: The sets were run either by the main electric current or by dry, light, and portable batteries. No problems were met in carrying out the project in the city as municipal electric current could be used. However, in most of the villages there was no electric supply. Therefore, we had to use dry batteries. These dry batteries were sent to us from the United States and, of course, they would get weaker in time. When these dry batteries expired we could not find substitutes on the local market. The project control officer resorted to the use of the ordinary car battery (accumulator 12 volts) as a quick solution to the problem. This idea, which is still in the process of development and improvement, proved successful. These car batteries are very inexpensive to maintain and are available in any country.

(3) Perimeters: We had perimeters with mirrors in the middle that misled people of very limited intelligence. They expected to see the moving target and the image of their eyes appear in the mirror. We had to change this mirror and replace it with a stationary, small white target upon which to fix the eye. In this way the time required for perimetry was shortened to about 1 to 1½ minutes for each eye.

Now, for some comments regarding the cooperation of the population as a whole in the city. Some well-to-do families refused to admit the screening teams into their homes on the pretext that they were looked after by their own family doctors. But for the tact of the social worker in convincing many of them, the number of uncooperative families would have risen to a higher number. We had only 19 families out of about 1,000 families who refused to be examined.

Those cases screened out as blind were early in the project referred to ophthalmologists' private clinics for reexamination. It was believed that this would save the time of the ophthalmologists who would not have to go to the various homes to examine patients. This did not turn out to be very feasible because many of the referrals were hesitant to go to these ophthalmologists for fear they would have to pay consultation fees. As a result it was necessary to have the patients come to the university hospital outpatient clinic in the afternoons. When they were reluctant to come, or ill health or old age was a factor, we sent a social worker to bring them in a car and then

take them back home. Where the patients were invalids, the ophthalmologists went to their homes to have them examined.

In order to persuade people in the rural sector to come in for sight-screening, we decided to add treatment to the services rendered. In a country like ours, the general awareness of the value of projects such as this is at a rather low level. Eyedrops and ointments were given out free of charge. Those who were in need of long-term treatment or surgery were transferred to the university hospital. We stressed this point in particular in publicizing the project. Families who lived near the screening centers usually came together for examination. However, where families lived at great distances from the screening centers, the vision-testing teams were obliged to meet them where they lived. Thus, all the families in the rural sector were sight-screened. Not a single family refused to cooperate. In view of the fact that the ophthalmologists accompanied the screening teams and reexamined the referred cases on the spot, there was no problem of the referred cases not presenting themselves for reexamination.

There was no difficulty whatsoever in the urban areas in transporting the apparatus and the teams. They used taxicabs which are quite inexpensive. In the rural sector, however, transportation cropped up as a problem since some of the taxicab drivers, on learning the destinations, occasionally refused to head for the farms for fear of the rugged roads. In the rainy season, reaching some of the villages was impossible. Transportation to and from the rural sector was the major problem met with in the project so far. If we had been provided with a small bus, matters would have been much easier, and some expenses would have been saved. This concludes the review of the major difficulties of Phase I.

We are now in the middle of Phase II and have almost finished the rural part of that phase. We have examined about 55,000 people in the rural sector and have about 2 or 3 months' work of examinations ahead to finish the rural sector.

In the urban sector of Phase II we expect to find more difficulties. Despite the publicity campaign we intend to put into action, we do not expect the city people to flock to our screening centers in large numbers. This is due to the fact that the citizens of the urban areas have, in general, a poor awareness of the value of such projects as well as the fact that they are fully occupied in the various professions and trades. The examination centers will go into every street. We had originally thought of having the examination centers in certain places, such as, schools, social union centers, and clubs. However, we now believe this will not be feasible. Therefore, we are prepared for teams to go with the sets of apparatus from street to street, from apartment to apartment, just as in Phase I. Of course, in Phase II this would be quite a problem because of the large number of people expected.

As to Phase III, the major problem expected will be to locate the same individuals who were previously sight-screened in the random sampling in Phase I; attempts will be made to locate for reexamination those who migrated or changed their residence. In the rural section many problems are expected as new plans are being made for the remodeling of the countryside, particularly in redistributing populations in overcrowded villages among newly built ones.

The preliminary findings of Phase I follow:

(1) A 4-percent random sample of households (5,150 persons) of two urban districts was visually screened in Alexandria, Egypt. Similarly screened was a 4.0-percent sample of households (5,856 persons) of 23 villages in a neighboring governorate. The disparity in number between the 5,856 persons examined in the rural areas and the 5,150 in the urban areas resulted mainly from the fact that in the rural areas there are usually found large "extended" families where several generations live together in one hut. This is much less prevalent in the urban areas. Since the sample was by households it was inevitable that quite a few such "extended" families would fall into the sample in the rural areas. (Table 1.)

(2) Approximately 40 percent of those examined in urban areas were males and about 60 percent females. The reason

TABLE 1.—*Areas sampled and sample size*

Urban (in Alexandria)					Rural (villages outside of Alexandria)				
District	Subdistrict	Estimated population April 1965	Sample examined		Size of villages	Number of villages	Estimated population April 1965	Sample examined	
			Number	Percent				Number	Percent
Attarine	7	80,020	3,230	4.0	Under 5,000	14	47,850	2,237	4.7
Manshia	4	47,790	1,920	4.0	5,000 to 9,999	6	37,890	1,719	4.5
					10,000 to 14,999	2	25,240	1,126	4.5
					15,000 or over	1	15,960	774	4.8
Total	11	127,810	5,150	4.0		23	126,940	5,856	4.6

TABLE 2.—*Individuals examined in Phase I in urban areas*

Age in years	Attarine			Manshia			Total		
	M	F	T	M	F	T	M	F	T
Under 5	2	5	7	3	0	3	5	5	10
5–9	208	199	407	135	177	312	343	376	719
10–14	276	287	563	146	228	374	422	515	937
15–19	171	281	452	105	198	303	276	479	755
20–24	93	174	267	54	94	148	147	268	415
25–29	78	200	278	34	71	105	112	271	383
30–34	102	145	247	30	107	137	132	252	384
35–39	96	144	240	32	95	127	128	239	367
40–44	82	96	178	34	71	105	116	167	283
45–49	76	87	163	48	46	94	124	133	257
50–54	63	83	146	24	44	68	87	127	214
55–59	60	40	100	20	36	56	80	76	156
60–64	37	49	86	19	20	39	56	69	125
65–69	14	22	36	11	17	28	25	39	64
70–74	14	23	37	6	8	14	20	31	51
75 and over	8	15	23	6	1	7	14	16	30
Total	1,380	1,850	3,230	707	1,213	1,920	2,087	3,063	5,150
Percent	42.7	57.3	100.0	36.8	63.2	100.0	40.5	59.5	100.0

for this appreciably greater number of females examined, compared to males, is being investigated. Some 55 percent of those examined were under 25 years and 3 percent were 65 years and over. No significant differences were noted between the age distributions of males and females. (Table 2.)

(3) Of those examined in the rural areas, about 49 percent were males and 51 percent females. About 48 percent were under 25 years and 2 percent were 65 years and over. Males and females did not differ markedly in their age distribution. (Table 3.)

(4) In the urban areas the blind under 25 years accounted for about 7 percent of cases compared to 55 percent of those examined. The urban blind, 65 years and over, constituted about 29 percent of all blind but, from Table 2, only 3 percent of those examined. Among males, the blind under 25 years accounted for 12 percent of all male blind (compared to 4 percent among females) while those 65 years and over accounted

TABLE 3.—*Individuals examined in Phase I in rural areas*

Age in years	Villages under 5,000			Villages 5,000 to 9,999			Villages 10,000 to 14,999			Villages 15,000 or over			Total		
	M	F	T	M	F	T	M	F	T	M	F	T	M	F	T
Under 5	-----	6	6	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	6	6
5–9	130	101	231	105	90	195	70	69	139	59	43	102	364	303	667
10–14	244	195	439	155	148	303	98	98	196	80	60	140	577	501	1,078
15–19	133	135	268	82	89	171	67	68	135	40	35	75	322	327	649
20–24	56	85	141	57	86	143	30	33	63	16	27	43	159	231	390
25–29	74	112	186	53	91	144	34	61	95	34	33	67	195	297	492
30–34	81	131	212	75	100	175	32	65	97	28	40	68	216	336	552
35–39	96	122	218	70	88	158	44	55	99	33	37	70	243	302	545
40–44	85	62	147	57	66	123	56	52	108	32	23	55	230	203	433
45–49	58	45	103	52	42	94	28	25	53	28	14	42	166	126	292
50–54	62	51	113	43	39	82	21	24	45	17	22	39	143	136	279
55–59	38	32	70	29	18	47	20	14	34	20	11	31	107	75	182
60–64	29	24	53	23	24	47	16	16	32	12	10	22	80	74	154
65–69	20	7	27	12	9	21	7	4	11	10	2	12	49	22	71
70–74	8	9	17	7	1	8	4	8	12	1	1	2	20	19	39
75 and over	4	2	6	5	3	8	3	4	7	4	2	6	16	11	27
Total	1,118	1,119	2,237	825	894	1,719	530	596	1,126	414	360	774	2,887	2,969	5,856
Percent	50.0	50.0	100.0	48.0	52.0	100.0	47.1	52.9	100.0	53.5	46.5	100.0	49.3	50.7	100.0

for 36 percent of the male blind (as compared to some 25 percent among females). (Table 4.)

TABLE 4.—*Blind persons, by age and sex, in urban areas*

Age in years	Male		Female		Total	
	Number	Percent	Number	Percent	Number	Percent
Under 5	-----	-----	-----	-----	-----	-----
5–9	2	8.0	-----	-----	2	2.7
10–14	1	4.0	1	2.0	2	2.7
15–19	-----	-----	1	2.0	1	1.4
20–24	-----	-----	-----	-----	-----	-----
25–29	-----	-----	-----	-----	-----	-----
30–34	-----	-----	3	6.1	3	4.1
35–39	2	8.0	2	4.1	4	5.4
40–44	1	4.0	4	8.2	5	6.8
45–49	2	8.0	1	2.0	3	4.1
50–54	1	4.0	6	12.2	7	9.5
55–59	5	20.0	6	12.2	11	14.9
60–64	2	8.0	13	26.5	15	20.3
65–69	3	12.0	6	12.2	9	12.2
70–74	3	12.0	4	8.2	7	9.5
75 and over	3	12.0	2	4.1	5	6.8
Total	25	100.0	49	100.0	74	100.0

(5) The blindness prevalence rate in urban areas was 1,437 per 100,000 with the rate in males 1,198 and in females 1,600, a difference which was not statistically significant at the 5-percent level. In Attarine the rate was 1,300 and in Manshia 1,667 per 100,000. No significant difference was found between the male and female prevalence rates at the 5-percent level in either of the districts or between the districts. The above rates should be age-adjusted for more meaningful comparisons. (Table 5.)

(6) The blind under 25 years in rural areas accounted for some 8 percent of the

TABLE 5.—*Blindness prevalence and rates, by district and sex, in urban areas*

Sex	Attarine		Manshia		Total	
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
Male	17	1,231.9	8	1,131.5	25	1,197.9
Female	25	1,351.3	24	1,978.6	49	1,599.7
Total	42	1,300.3	32	1,666.7	74	1,436.9

cases (compared to 48 percent of those examined). The rural blind 65 years and over constituted some 25 percent of all blind but, according to Table 3, only 2 percent of those examined. Among males, the blind under 25 years constituted 10 percent all male blind (compared to 7 percent among females) while those 65 years and over accounted for 34 percent of the male blind (compared to about 20 percent among females). (Table 6.)

TABLE 6.—*Blind persons, by age and sex, in rural areas*

Age in years	Male		Female		Total	
	Number	Percent	Number	Percent	Number	Percent
Under 5						
5–9	2	2.1	1	0.6	3	1.1
10–14	4	4.1	3	1.7	7	2.6
15–19	1	1.0	6	3.4	7	2.6
20–24	3	3.1	2	1.1	5	1.8
25–29	3	3.1	2	1.1	5	1.8
30–34	3	3.1	11	6.2	14	5.1
35–39	4	4.1	8	4.5	12	4.4
40–44	3	3.1	10	5.6	13	4.7
45–49	4	4.1	10	5.6	14	5.1
50–54	12	12.4	27	15.3	39	14.2
55–59	12	12.4	28	15.8	40	14.6
60–64	13	13.4	34	19.2	47	17.2
65–69	16	16.5	17	9.6	33	12.0
70–74	8	8.2	9	5.1	17	6.2
75 and over	9	9.3	9	5.1	18	6.6
Total	97	100.0	177	100.0	274	100.0

(7) In the rural areas the blindness prevalence rate was 4,679 per 100,000. In general, the more populated villages seem to have higher rates but the differences were not significant at the 5-percent level. In males the blindness prevalence rate was 3,360 and in females 5,962 per 100,000, the difference was statistically significant at the 5-percent level. The rates for females were consistently higher than male rates, irrespective of size of village. It should be mentioned that the differences between the urban and rural male rates and between the urban and rural female rates were statistically significant at the 5-percent level. The above rates should be age-standardized for more meaningful comparisons. (Table 7.)

(8) In view of the small number of youngsters under 5 years examined, as mentioned above, age-specific prevalence rates by sex or cause were compiled only for individuals 5 years and over, starting with the age group 5–19 years. The urban age-specific prevalence rate rose steadily with age from 207 in the group 5–19 years to 16,667 per 100,000 in the group 75 years and over. Marked increases in rates were evident in the age groups above age 45. This was true for both males and females except that the female rate reached its peak in the age group 65–74 years and then dropped slightly. In males, the increase from the youngest to the oldest group was from 288 to 21,429 and, in females, from 146 to 12,500 per 100,000. Since the rates in the highest age groups are based on relatively few cases, caution should be exercised in the interpretation of such rates. (Table 8.)

TABLE 7.—*Blindness prevalence and rates by size of village and sex, in rural areas*

Sex	Under 5,000		5,000 to 9,999		10,000 to 14,999		15,000 and over		Total	
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
Male	23	2,057.2	36	4,363.6	21	3,962.3	17	4,106.3	97	3,359.9
Female	62	5,540.7	44	4,921.7	46	7,718.1	25	6,944.4	177	5,961.6
Total	85	3,799.7	80	4,653.9	67	5,950.3	42	5,426.3	274	4,679.0

TABLE 8.—*Blindness prevalence and rates, by age and sex, in urban areas*

Age	Male			Female			Total		
	Number examined	Blind	Rate per 100,000	Number examined	Blind	Rate per 100,000	Number examined	Blind	Rate per 100,000
5–19	1,041	3	288.2	1,370	2	146.0	2,411	5	207.4
20–44	635	3	472.4	1,197	9	751.9	1,832	12	655.0
45–64	347	10	2,881.8	405	26	6,419.8	752	36	4,787.2
65–74	45	6	13,333.3	70	10	14,285.7	115	16	13,913.0
75 and over	14	3	21,428.6	16	2	12,500.0	30	5	16,666.7
Total	2,082	25	1,200.8	3,058	49	1,602.4	5,140	74	1,439.7

(9) The rural age-specific prevalence rate increased from 710 in the age group 5–19 years to 66,667 per 100,000 in the group 75 years and over. This increase, in males, was from 554 to 56,250 and, in females, from 884 to 81,818 per 100,000. Such increases in rate with age were generally found irrespective of size of village if there were sufficient cases in an age group to permit the calculation of reliable rates. Size of village appeared to have no significant influence. (Tables 9, 10, and 11.)

TABLE 9.—*Blindness prevalence and rates, by age, in rural areas—Both sexes*

Age	Under 5,000			5,000 to 9,999			10,000 to 14,999			15,000 and over			Total		
	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000
5–19	938	3	319.8	669	5	747.4	470	6	1,276.6	317	3	946.4	2,394	17	710.1
20–44	904	16	1,769.9	743	14	1,884.3	462	12	2,597.4	303	7	2,310.2	2,412	49	2,031.5
45–64	339	47	13,864.3	270	39	14,444.4	164	32	19,512.2	134	22	16,417.9	907	140	15,435.5
65–74	44	15	34,090.9	29	16	55,172.4	23	14	60,869.6	14	5	35,714.3	110	50	45,454.5
75 and over	6	4	66,666.7	8	6	75,000.0	7	3	42,857.1	6	5	83,333.3	27	18	66,666.7
Total	2,231	85	3,810.0	1,719	80	4,653.9	1,126	67	5,950.3	774	42	5,426.4	5,850	274	4,683.8

TABLE 10.—*Blindness prevalence and rates, by age, in rural areas—Males*

Age	Under 5,000			5,000 to 9,999			10,000 to 14,999			15,000 and over			Total		
	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000
5–19	507	2	394.5	342	2	584.8	235	2	851.1	179	1	558.7	1,263	7	554.2
20–44	392	2	510.2	312	7	2,243.6	196	4	2,040.8	143	3	2,097.9	1,043	16	1,534.0
45–64	187	11	5,882.4	147	15	10,204.1	85	9	10,588.2	77	6	7,792.2	496	41	8,266.1
65–74	28	6	21,428.6	19	8	42,105.3	11	6	54,545.5	11	4	36,363.6	69	24	34,782.6
75 and over	4	2	50,000.0	5	4	80,000.0	3	-------	----------	4	3	75,000.0	16	9	56,250.0
Total	1,118	23	2,057.2	825	36	4,363.6	530	21	3,962.3	414	17	4,106.3	2,887	97	3,359.9

TABLE 11.—*Blindness prevalence and rates, by age, in rurual areas—Females*

Age	Under 5,000			5,000 to 9,999			10,000 to 14,999			15,000 and over			Total		
	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000	Number examined	Blind	Rates per 100,000
5–19	431	1	232.0	327	3	917.4	235	4	1,702.1	138	2	1,449.3	1,131	10	884.2
20–44	512	14	2,734.4	431	7	1,624.1	266	8	3,007.5	160	4	2,500.0	1,369	33	2,410.5
45–64	152	36	23,684.2	123	24	19,512.2	79	23	29,113.9	57	16	28,070.2	411	99	24,087.6
65–74	16	9	56,250.0	10	8	80,000.0	12	8	66,666.7	3	1	33,333.3	41	26	63,414.6
75 and over	2	2	100,000.0	3	2	66,666.7	4	3	75,000.0	2	2	100,000.0	11	9	81,818.2
Total	1,113	62	5,570.5	894	44	4,921.7	596	46	7,718.1	360	25	6,944.4	2,963	177	5,973.7

(10) In urban areas the prevalence rate for blindness due to cataract was highest, 525 per 100,000. Following cataract, with their rates per 100,000 were: purulent ophthalmia (409), myopia (175), glaucoma (78), and corneal ulcers due to bacterial infection (39). In males, blindness prevalence due to cataract also was highest with a rate of 432 per 100,000. The next affections in order, with their respective rates per 100,000 were: purulent ophthalmia (288), myopia (192), corneal ulcers due to bacterial infection (96), and glaucoma (48) in that order. In females, cataract prevalence headed the list with a rate of 589 per 100,000. The other rates in order of magnitude were: purulent ophthalmia (491), myopia (163), and glaucoma (98). It is interesting to note that the female rate for purulent ophthalmia was almost twice that of males. (Table 12.)

TABLE 12.—*Blindness prevalence and rates, by affection and sex, in urban areas*

Affection	Male			Female			Total		
	Number	Percent	Rate per 100,000	Number	Percent	Rate per 100,000	Number	Percent	Rate per 100,000
Cataract	9	36.0	432.3	18	36.7	588.6	27	36.5	525.3
Purulent ophthalmia	6	24.0	288.2	15	30.6	490.5	21	28.4	408.6
Myopia	4	16.0	192.1	5	10.2	163.5	9	12.2	175.1
Glaucoma	1	4.0	48.0	3	6.1	98.1	4	5.4	77.8
Corneal ulcers [1]	2	8.0	96.1				2	2.7	38.9
Other affections	3	12.0	144.1	8	16.3	261.6	11	14.9	214.0
Total	25	100.0	1,200.8	49	100.0	1,602.4	74	100.0	1,439.7

[1] Due to bacterial infection.

TABLE 13.—*Blindness prevalence and rates, by age and affection, in urban areas—Both sexes*

Age	Affection						
	Glaucoma	Myopia	Purulent ophthalmia	Corneal ulcer [1]	Cataract	Other affections	Total
	Number						
5–19				1		4	5
20–44	1	1	6	1	1	2	12
45–64	2	7	8		15	4	36
65–74	1	1	6		8		16
75 and over			1		3	1	5
Total	4	9	21	2	27	11	74
	Prevalence rate per 100,000						
5–19				41.5		165.9	207.4
20–44	54.6	54.6	327.5	54.6	54.6	109.2	655.0
45–64	266.0	930.9	1,063.8		1,994.7	531.9	4,787.2
65–74	869.6	869.6	5,217.4		6,956.6		13,913.2
75 and over			3,333.3		10,000.0	3,333.3	16,666.7
Total	77.8	175.1	408.6	38.9	525.3	214.2	1,439.7

[1] Due to bacterial infection.

The cataract prevalence rate rose with age in both sexes but leveled off in females at age group 65–74 years. The purulent ophthalmia rate reached its peak in the age group 65–74 years but kept on increasing in males. The small number of cases in the highest age groups means that the rates of each age groups should be interpreted with caution. (Tables 13, 14, and 15.)

As concerns etiology, senile degeneration had the highest prevalence rate, 525 per 100,000. Infectious diseases followed with a rate of 447. The former rate showed sharp increases with age starting with the age group 45–64 years while the latter rate showed marked increases starting with the age group 20–44 years. (Table 16.)

When cases were tabulated by affection and etiology, two major entities, namely cataract-senile degeneration and purulent ophthalmia-infectious diseases, accounted for almost two-thirds of the cases. (Table 17.)

(11) In rural areas the prevalence rate for blindness due to purulent opthalmia was the highest, 2,137 per 100,000 population. Next in magnitude were the rates for cataract (1,539), corneal ulcer due to bacterial infection (376), and glaucoma (325). In males, the rate for purulent ophthalmia led the list with 1,385 per 100,000 followed by rates for cataract (1,039), corneal ulcer due to bacterial infection (312), and glaucoma (277). The highest rate in females were that of purulent ophthalmia, 2,869 per 100,000, followed by cataract (2,025), corneal ulcer due to bacterial infection (439) and glaucoma (371). For every affection indicated above, the female rate exceeded the male. The female rate for purulent ophthalmia was over twice that for males while for cataract it was almost twice the male rate. (Table 18.)

The rate for purulent ophthalmia increased with age from 334 per 100,000 in age group 5–19 years to 14,545 in age groups 65–74 years, after which it

TABLE 14.—*Blindness prevalence and rates, by age and affection, in urban areas—Males*

Age	Affection						
	Glaucoma	Myopia	Purulent ophthalmia	Corneal ulcer [1]	Cataract	Other affections	Total
	Number						
5–19				1		2	3
20–44		1		1	1		3
45–64	1	2	3		3	1	10
65–74		1	2		3		6
75 and over			1		2		3
Total	1	4	6	2	9	3	25
	Prevalence rate per 100,000						
5–19				96.1		192.2	288.2
20–44		157.5		157.5	157.5		472.4
45–64	288.2	576.4	864.6		864.6	288.2	2,881.8
65–74		2,222.2	4,444.4		6,666.6		13,333.3
75 and over			7,142.9		14,285.8		21,428.6
Total	48.0	192.1	288.2	96.1	432.3	144.1	1,200.8

[1] Due to bacterial infection.

TABLE 15.—*Blindness prevalence and rates, by age and affection, in urban areas—Females*

Age	Affection						
	Glaucoma	Myopia	Purulent ophthalmia	Corneal ulcer [1]	Cataract	Other affections	Total
	Number						
5–19						2	2
20–44	1		6			2	9
45–64	1	5	5		12	3	26
65–74	1		4		5		10
75 and over					1	1	2
Total	3	5	15		18	8	49
	Prevalence rate per 100,000						
5–19						146.0	146.0
20–44	83.5		501.3			167.0	751.9
45–64	246.9	1,234.6	1,234.6		2,962.9	740.7	6,419.8
65–74	1,428.6		5,714.3		7,142.9		14,285.7
75 and over					6,250.0	6,250.0	12,500.0
Total	98.1	163.5	490.5		588.6	261.6	1,602.4

[1] Due to bacterial infection.

TABLE 16.—*Blindness prevalence and rates, by age and etiology, in urban areas—Both sexes*

Age	Etiology								
	Infectious diseases	Injuries and poisonings	Diabetes	Senile degeneration	Vascular diseases	Prenatal influences	Unknown to science	Not reported or determined	Total
	Number								
5–19	1					1		3	5
20–44	7			1			1	3	12
45–64	8	1	3	15			2	7	36
65–74	6			8			1	1	16
75 and over	1			3				1	5
Total	23	1	3	27		1	4	15	74
	Prevalence rate per 100,000								
5–19	41.5					41.5		124.5	207.4
20–44	382.1			54.6			54.6	163.8	655.4
45–64	1,063.8	133.0	399.0	1,994.7			266.0	930.9	4,787.2
65–74	5,217.4			6,956.6			869.6	869.6	13,913.2
75 and over	3,333.3			10,000.0				3,333.3	16,666.7
Total	447.5	19.5	58.4	525.3		19.5	77.8	292.0	1,439.7

TABLE 17.—*Blindness prevalence, by affection and etiology, in urban areas—Both sexes*

Affection	Etiology								
	Infectious diseases	Injuries and poisonings	Diabetes	Senile degeneration	Vascular diseases	Prenatal influences	Unknown to science	Not reported or determined	Total
	Number								
Glaucoma							4		4
Myopia								9	9
Purulent ophthalmia	21								21
Corneal ulcer [1]	2								2
Cataract				27					27
Other affections		1	3			1		6	11
Total	23	1	3	27		1	4	15	74
	Percent								
Glaucoma							5.4		5.4
Myopia								12.2	12.2
Purulent ophthalmia	28.4								28.4
Corneal ulcer [1]	2.7								2.7
Cataract				36.5					36.5
Other affections		1.4	4.1			1.4		8.1	15.0
Total	31.1	1.4	4.1	36.5		1.4	5.4	20.3	100.0

[1] Due to bacterial infection.

TABLE 18.—*Blindness prevalence and rates by, affection and sex, in rural areas*

Affection	Male			Female			Total		
	Number	Percent	Rate per 100,000	Number	Percent	Rate per 100,000	Number	Percent	Rate per 100,000
Purulent ophthalmia	40	41.2	1,385.5	83	46.9	2,801.2	123	44.9	2,102.6
Cataract	30	30.9	1,039.1	60	33.9	2,025.0	90	32.8	1,538.5
Myopia				2	1.1	67.5	2	0.7	34.2
Corneal ulcer [1]	9	9.3	311.7	13	7.3	438.7	22	8.0	376.1
Glaucoma	8	8.2	277.1	11	6.2	371.2	19	6.9	324.8
Other affections	10	10.3	364.4	8	4.5	270.0	18	6.6	307.7
Total	97	100.0	3,359.9	177	100.0	5,973.7	274	100.0	4,683.8

[1] Due to bacterial infection.

decreased somewhat. This was true for both males and females with the female rate considerably higher than the male rate in each age group. The cataract rate increased with age from a rate of 83 per 100,000 in age group 5–19 years to 40,740 in age group 75 years and over. The female rate greatly exceeded the male rate in each age group. (Tables 19, 20, and 21.)

TABLE 19.—*Blindness prevalence and rates, by age and affection, in rural areas—Both sexes*

Age	Affection						
	Glaucoma	Myopia	Purulent ophthalmia	Corneal ulcer [1]	Cataract	Other affections	Total
	Number						
5–19			8	1	2	6	17
20–44		1	38	3	3	4	49
45–64	13	1	58	14	49	5	140
65–74	4		16	3	25	2	50
75 and over	2		3	1	11	1	18
Total	19	2	123	22	90	18	274
	Prevalence rate per 100,000						
5–19			334.2	41.8	83.5	250.6	710.1
20–44		41.5	1,575.5	124.4	124.4	165.8	2,031.5
45–64	1,433.3	110.3	6,394.7	1,543.5	5,402.4	551.3	15,435.5
65–74	3,636.4		14,545.5	2,727.3	22,727.3	1,818.2	45,454.5
75 and over	7,407.4		11,111.1	3,703.7	40,740.7	3,703.7	66,666.7
Total	324.8	34.2	2,102.6	376.1	1,538.5	307.7	4,683.8

[1] Due to bacterial infection.

TABLE 20.—*Blindness prevalence and rates by, age and affection, in rural areas—Males*

Age	Affection						
	Glaucoma	Myopia	Purulent ophthalmia	Corneal ulcer [1]	Cataract	Other affections	Total
	Number						
5–19			2			5	7
20–44			12	2		2	16
45–64	4		19	5	11	2	41
65–74	2		6	2	13	1	24
75 and over	2		1		6		9
Total	8		40	9	30	10	97
	Prevalence rate per 100,000						
5–19			158.4			396.0	554.2
20–44			1,150.5	191.8		191.8	1,534.0
45–64	806.5		3,830.6	1,008.1	2,217.7	403.2	8,266.1
65–74	2,898.6		8,695.7	2,898.6	18,840.6	1,449.3	34,782.6
75 and over	12,500.0		6,250.0		37,500.0		56,250.0
Total	277.1		1,385.5	311.7	1,039.1	346.3	3,359.9

[1] Due to bacterial infection.

TABLE 21.—*Blindness prevalence and rates, by age and affection, in rural areas—Females*

Age	Affection						
	Glaucoma	Myopia	Purulent ophthalmia	Corneal ulcer [1]	Cataract	Other affections	Total
	Number						
5–19			6	1	2	1	10
20–44		1	26	1	3	2	33
45–64	9	1	39	9	38	3	99
65–74	2		10	1	12	1	26
75 and over			2	1	5	1	9
Total	11	2	83	13	60	8	177
	Prevalence rate per 100,000						
5–19			530.5	88.4	176.8	88.4	884.2
20–44		73.0	1,899.2	73.0	219.1	146.1	2,410.5
45–64	2,189.8	243.3	9,489.1	2,189.8	9,245.7	729.9	24,087.6
65–74	4,878.0		24,390.2	2,439.0	29,268.3	2,439.0	63,414.6
75 and over			18,181.8	9,090.9	45,454.5	9,090.9	81,818.2
Total	371.2	67.5	2,801.2	438.7	2,025.0	270.0	5,973.7

[1] Due to bacterial infection.

TABLE 22.—*Blindness prevalence and rates, by age and etiology, in rural areas—Both sexes*

Age	Etiology								
	Infectious diseases	Injuries and poisonings	Diabetes	Senile degeneration	Vascular diseases	Prenatal influences	Unknown to science	Not reported or determined	Total
	Number								
5–19	9	2				3		3	17
20–44	42			2		4		1	49
45–64	74			48		3	13	2	140
65–74	19	1		25	1		4		50
75 and over	4			11			2	1	18
Total	148	3		86	1	10	19	7	274
	Prevalence rate per 100,000								
5–19	376.0	83.6				125.4		125.4	710.1
20–44	1,741.5			83.0		165.9		41.5	2,031.5
45–64	8,158.9			5,292.2		330.9	1,433.3	220.6	15,435.5
65–74	17,272.8	909.1		22,727.3	909.1		3,636.4		45,454.5
75 and over	14,814.8			40,740.7			7,407.4	3,703.7	66,666.7
Total	2,530.0	51.3		1,470.1	17.1	170.9	324.7	119.7	4,683.8

With respect to etiology, infectious diseases had the highest rate, 2,530 per 100,000. Senile degeneration followed with a rate of 1,470. This is just the reverse of the situation in the urban areas. The rate for infectious diseases rose sharply in the age group 20–44 years and continued to increase until it hit a peak of 17,273 per 100,000 at age group 65–74 years and then decreased somewhat. The rate for senile degeneration rose sharply in the age group 45–64 years and continued its upward trend. It reached a peak of 40,741 per 100,000 in the age group 75 years and over. (Table 22.)

An analysis by affection and etiology of the rural cases revealed that purulent ophthalmia-infectious diseases and cataract-senile degeneration together accounted for over three-quarters of all rural cases. (Table 23.)

Since the above data are preliminary findings, no attempt will be made in this paper to interpret their meaning.

TABLE 23.—*Blindness prevalence, by affection and etiology, in rural areas—Both sexes*

Affection	Etiology								
	Infectious diseases	Injuries and poisonings	Diabetes	Senile degeneration	Vascular diseases	Prenatal influences	Unknown to science	Not reported or determined	Total
	Number								
Glaucoma							19		19
Myopia						2			2
Purulent ophthalmia	123								123
Corneal ulcer	22								22
Cataract		2		86		1		1	90
Other affections	3	1			1	7		6	18
Total	148	3		86	1	10	19	7	274
	Percent								
Glaucoma							6.9		6.9
Myopia						0.7			0.7
Purulent ophthalmia	44.9								44.9
Corneal ulcer	8.0								8.0
Cataract		0.7		31.4		0.4		0.4	32.8
Other affections	1.1	0.4			0.4	2.6		2.2	6.7
Total	54.0	1.1		31.4	0.4	3.6	6.9	2.6	100.0

APPENDIX F

LIST OF PARTICIPANTS
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- Robert L. Robinson, Research Associate, Department of Research

National Society for the Prevention of Blindness, Inc.
Mrs. Elizabeth M. Hatfield, Consultant in Statistics
Dr. Ralph G. Hurlin, Chairman, Subcommittee on Classification, Committee on Operational Research

Canada

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Miss Susan J. Hennighausen, National Supervisor, Prevention of Blindness and Eye Service Department

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Catholic Guild for All the Blind
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Dr. Leo H. Riley, Director, American Center for Research in Blindness and Rehabilitation

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Dr. Gordon B. Connor, Director, Professional Services

Rehabilitation Codes Inc.
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